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International Federation  
of Red Cross and Red Crescent Societies



# A vital partnership:

the work of GNP+ and the International Federation  
of Red Cross and Red Crescent Societies on HIV/AIDS

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UNAIDS BEST PRACTICE COLLECTION

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Report researched and written by Lindsay Knight

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## A UNAIDS BEST PRACTICE CASE STUDY

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# A vital partnership: the work of GNP+ and the International Federation of Red Cross and Red Crescent Societies on HIV/AIDS



International Federation  
of Red Cross and Red Crescent Societies



Joint United Nations Programme on HIV/AIDS

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# Preface

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This case study aims to inform on the partnership experience, brokered by UNAIDS, between the International Federation of the Red Cross and Red Crescent Societies (IFRC) and the Global Network of People Living with HIV/AIDS (GNP+). The experience of building this partnership has been documented to help promote similar collaborative ventures involving National Red Cross and Red Crescent Societies in their work on HIV/AIDS at country level. The case study provides a detailed recount of the process that led to the partnership, elaborating on background and examples.

The document is also intended to benefit other organizations seeking to forge innovative partnerships to deal with the HIV/AIDS pandemic. It describes how links have been initiated and maintained between organisations of very different missions and visions. The document further demonstrates the personal and institutional commitments that have contributed to the partnership process. This publication shows how two different organisations could join forces, openly and collaboratively to arrive at one common goal, without compromising their respective core missions, integrity and identity.

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# Introduction

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On 26 June 2001, at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS on HIV/AIDS), one side event attracted a large audience – and some distinguished guests, including the UN Secretary-General, Kofi Annan. This meeting, organised by the International Federation of Red Cross and Red Crescent Societies, was initially planned as an intimate dialogue between official UNGASS on HIV/AIDS delegates and people living with HIV/AIDS, by invitation only. But as news of its subject matter spread, the demand for invitations grew. When Mr Annan's office called to ask if he might attend, the organisers, realizing that this had become a major event, changed venues to the largest meeting room (space for 855 people) in the UN building and opened it to everyone.

The event was another step towards establishing a potentially powerful new alliance, a partnership between GNP+, the Global Network of People Living with HIV/AIDS, and the International Federation of Red Cross and Red Crescent Societies. Red Cross and Red Crescent volunteers and GNP+ members spoke about their experiences living with HIV/AIDS, including the stigma and discrimination they faced. In a powerful image the UN Secretary-General gathered the GNP+ members and the Federation people living with HIV/AIDS around him for a photo opportunity. He then welcomed an alliance 'that sends a powerful message in breaking the silence around social stigma.' He praised the two organizations for showing how to make partnership effective.



Kofi and Nane Annan with GNP+ and Federation people living with HIV at the UNGASS on HIV/AIDS side event.

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***'By engaging in this partnership, the Red Cross and Red Crescent wants to send a clear message to the world that our emblem will protect people living with HIV/AIDS. We will accept no discrimination and will commit ourselves to fighting stigma wherever we meet it.'***

President of the International Federation (in 2001), Dr Astrid N. Heiberg.

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This is an intriguing partnership, though in many respects an unequal one; it has huge potential. It is an alliance brokered by UNAIDS, the United Nations' Joint Programme on HIV/AIDS; one of UNAIDS' key roles is to coordinate across sectors to ensure the most effective response against the epidemic. Partnerships with a wide and diverse range of actors are encouraged.

As the largest humanitarian organisation in the world, the International Federation of Red Cross and Red Crescent Societies is well placed to tackle the HIV/AIDS epidemic. Its seven fundamental Principles – humanity, impartiality, neutrality, independence, voluntary service, unity and universality – contribute to an effective response to the epidemic. An effective response also needs leadership and mobilisation of resources from governments; the Red Cross and Red Crescent National Societies are auxiliary to their respective governments in their humanitarian work, and as such work very closely with government departments. In many countries, ex-government ministers sit on the board of the National Society. The Federation attracts funds from donors with large resources as well as from the general public. It works with and understands a diversity of commu-

nities and cultures. It has 100 million members and volunteers worldwide, at least two million in Africa. In many developing countries, including those hardest hit by the HIV/AIDS epidemic, the National Societies provide valuable health services. They often run countries' blood banks and ambulance services.

The emblems of the International Red Cross and Red Crescent Movement are perhaps the best known in the world. These emblems signify protection for vulnerable people everywhere, and as such should be a powerful tool in the fight against HIV/AIDS.



Bai Bagasao of UNAIDS with Stu Flavell at the Federation HQ in Geneva for the 8 May 2002 launch of the global anti-stigma campaign.

But until recently, the huge potential of the Movement for tackling HIV/AIDS was not fully realized. At international and national levels, there was a lack of vision and commitment. Stigma and discrimination were not unknown within the Movement. Although there were some outstanding examples of good work on HIV/AIDS, such as home-based care programmes and peer education, they had not been scaled up to provide national coverage, nor did such initiatives exist in every country suffering from the impact of the epidemic.

GNP+ and its networks, on the other hand, have the vision, the commitment and the will to make the world a safer place for people living with HIV/AIDS. But GNP+ lacks the resources – both human and financial - to carry them out. The Secretariat in Amsterdam has a full-time staff of four – at the most – and across the world many of its networks and branches operate with even fewer staff members. As activists, GNP+ members confront governments and international organisations, advocating for better access to care and treatment. But without sufficient resources, skills and capacity, their voices are not always heard.

## Aim of the Case Study

The aim of this case study is to document and analyse the whys and wherefores of the partnership between the International Federation and GNP+, and its progress from the early discussions in late 2000 until mid 2003. It focuses on work at a global level and nationally in some African countries and in Honduras, with reference to the partnership in other regions. It is an attempt to offer a frank account of what the partnership means, at global, national and grassroots levels; to reflect on the challenges and successes, and to offer lessons learned, for other organisations as well as for the two partners.

## The GIPA principle

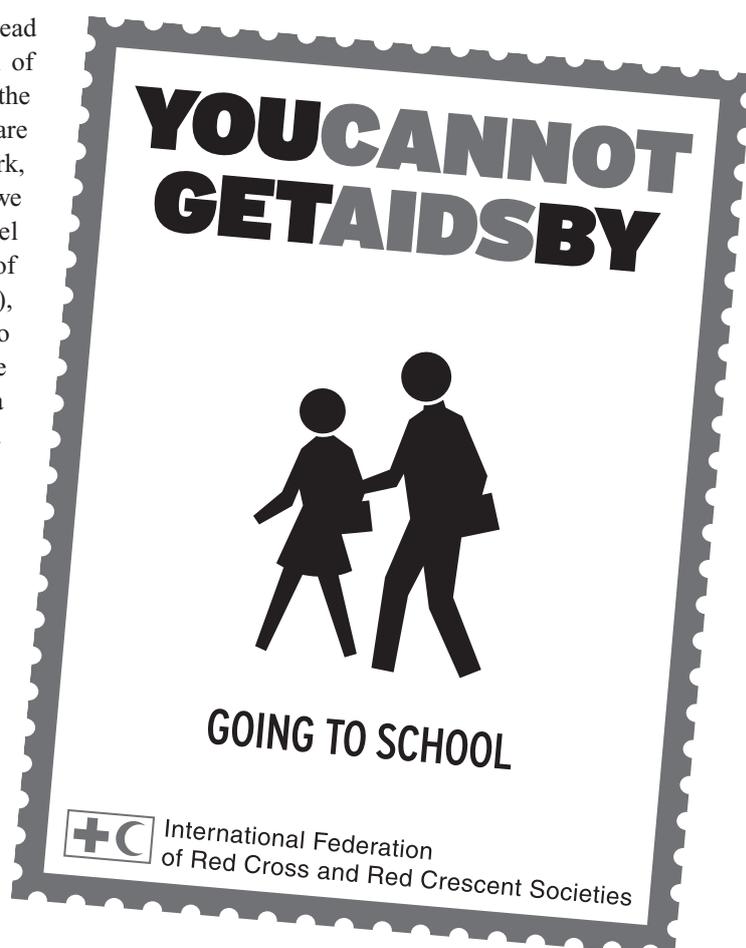
The principle of GIPA (the Greater Involvement of People infected or affected by HIV/AIDS) was formalized in the Declaration signed by 42 countries at the Paris AIDS Summit in 1994. The Paris GIPA meeting was taking the 'Denver principles' (See Annex) a step further and building on them. The value of people living with HIV/AIDS participating in work to combat the epidemic is constantly cited in documents or referred to at conferences and workshops. The Declaration of Commitments from the 2001 UNGASS on HIV/AIDS called for the 'strengthening by 2003 of mechanisms that involve ... civil society partners and PLWHA in the fight against HIV/AIDS.'

But too often only lip service is paid to this concept. In a 1999 UNAIDS report (From principle to Practice: GIPA, BP), J van Roey writes: 'GIPA is not reflected in national policies and programmes in any concerted or large-scale way, and there is an almost total lack of mechanisms permitting or encouraging PLWHA experiences, perceptions or skills to be considered (much less utilized).' In several documents three and four years later, UNAIDS (for example, in two reports from its Programme Coordinating Board) has stressed that PLWHA are an under-used resource in the response.

The partnership between the Federation and GNP+ is the first time that such a sizeable organisation has committed itself to working with PLWHA and in such a public way. It is the first attempt to work with the GIPA principle on a large scale. One of the tests of its success will be to measure how thoroughly PLWHA are participating in policy-making and programme implementation, and how integrated they are throughout the Federation – at Secretariat and Regional levels – and within National Societies.

This partnership is very new, less than three years old at the time of writing this case study, and several of the people interviewed expressed the view that it was too early to document the partnership. Indeed many National Societies are still struggling to respond in any way to the epidemic.

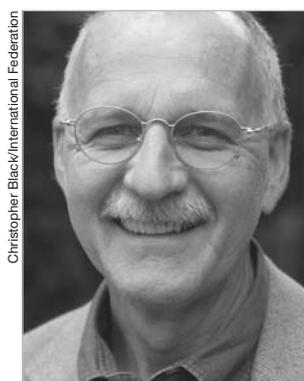
However, as Dr Alvaro Bermejo, Head of Health and Care, International Federation of Red Cross and Red Crescent Societies, told the 2001 World Health Assembly in Geneva: 'We are still learning how to make ... partnerships work, but we do not have the luxury of waiting until we know how everything will work.' Michael Angaga, the Coordinator of the Network of African People living with HIV/AIDS (NAP+), said: 'The partnership is perhaps too new to document but this is a race against time. We're fighting a war, and we can't afford to waste a minute.' Dorothy Odhiambo, who works with both the Federation and NAP+ in East Africa, has emphasised the 'urgent need to identify and understand conditions that make this kind of partnership succeed ... because it could act as a powerful mechanism in addressing ... stigma and discrimination, and access to comprehensive care and support.'



## The start of the partnership

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The idea for the partnership came from Calle Almedal, Senior Adviser, Partnerships Development, at UNAIDS. In 2000 he had initiated discussions between GNP+ and the Federation on stigma eradication. As a former member of staff of the Norwegian Red Cross, Almedal knew the potential of the Movement and its emblems – ‘probably the most powerful humanitarian symbols in the world and antidiscriminatory on their own.’ As a member of UNAIDS Partnerships Unit, he is committed to brokering innovative partnerships that expand the response to the epidemic.



Calle Almedal, UNAIDS.

He focuses on identifying large civil society organisations or entities that have the potential to make a difference in the field of HIV/AIDS. If they don't have the technical capacity, they can be partnered with an organisation that does have that capacity. He recognised the synergy of a possible partnership between GNP+ and the International Federation: ‘People living with HIV/AIDS would make a valuable input to the Federation's work and the Federation would protect the rights of PLWHA. There could be a clear win/win situation for all involved’

Almedal's idea appealed to both organisations and, significantly, to a key group of people within the Federation. Over the next few months, this group along with GNP+ members put considerable effort and enthusiasm into the project to ensure that it would develop and survive.

Both the Federation and GNP+ were at a stage in their development when such a ‘big idea’ was attractive. GNP+ and its networks lacked the resources to grow to the scale that was required. The Federation was having to confront the fact that it had not tackled the worst epidemic experienced by mankind on the scale expected of such an organisation. (See sections below for more detail on both organisations' activities.)

In November 2000, following discussions with Dr Alvaro Bermejo, Head of Health and Care at the Federation, it was agreed that Matthias Schmale, Head of Organisational Development Department, would make an exploratory visit to GNP+'s small, rather scruffy basement office in the centre of Amsterdam. The enthusiasm of Joseph Scheich, the then International Coordinator of GNP+, was evident and Bermejo soon went himself for a second meeting.

‘They were very honest,’ recalled Stuart Flavell, who was working as a volunteer with GNP+ at the time of the first meetings and then later became the International Coordinator of GNP+. ‘They admitted they had a problem, that the Red Cross/Red Crescent had AIDS but they were not effectively working against the epidemic. Despite being the voice of humanity, there was stigma and discrimination within the Movement itself. They wanted to reorient the whole organisation.’

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***‘Rather like an alliance between the elephant and the flea,’***

remarked Stu Flavell, now GNP+'s International Director and present at the original meetings.’

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Following these meetings, Bermejo and Schmale had to ‘sell’ the idea of the partnership to senior management and governance of the Federation. This was not a simple task. They confronted anxieties, fears and stigma, all perhaps to be expected of a very traditional organisation.

Alvaro Bermejo did have the support of a core group of colleagues within the Secretariat and National Societies. In Geneva a group concerned about the inadequate response of the Federation to HIV/AIDS had formed itself soon after Bermejo joined the Federation's Health and Care Department. He and his colleagues then gained strength and inspiration from many National Society members and volunteers who attended the International AIDS Conference in Durban in July 2000. It was at Durban that Bermejo met Bernard Gardiner who was at the time Australian Red Cross HIV/AIDS Programme Manager and would later become Manager of the HIV/AIDS Global Programme at the Federation's Secretariat. Bermejo recognised that Gardiner was probably the most experienced in working with PLWHA within the Movement. It was also at the Durban conference that the idea for a video of personal testimonials from Federation staff and volunteers living with HIV/AIDS, was conceived. This video, entitled 'Living with...', launched in December 2000 and widely distributed from early 2001, stirred up similar emotions within the Federation to the partnership with GNP+.

What were these emotions? Some senior staff feared that the Federation might be 'taken over' by GNP+, somehow swallowed up by these activists who courted controversy. Considering the inequality of scale between the two organisations, it must have seemed far more likely to GNP+ that they would be taken over – and indeed it was a fear expressed by some of its members.

There was also underlying stigma and discrimination to confront. Some people within the Federation did not want to be taken over by people living with HIV/AIDS, to them an alien group. Despite its strong humanitarian principles, the Movement has throughout its history been diminished at times by discriminatory attitudes, including towards PLWHA. These attitudes cannot just be dismissed; they have to be confronted and dealt with if there is to be an effective response to the epidemic that must involve PLWHA at a highly participatory level.

The Federation and some of its members rationalised their discrimination in a number of ways. They were fearful of the consequences of the partnership for National Societies. 'Parents will not allow their children to come to the Red Cross and our volunteer base will suffer.' 'People will stop donating their money to National Societies.' It was also said that people would stop donating their blood to the Red Cross blood banks and that they wouldn't feel the blood from these banks was safe enough. At the same time, a large National Society was involved in litigation with PLWHA organisations linked to GNP+ because of transfusion-borne infections in the early days of the epidemic.

Conversely, Bermejo recalls another fear that he and several colleagues most committed to the partnership experienced. They were concerned that the idea for the partnership had come too late, that the Federation would not be welcomed by PLWHA. 'We worried that they would think too much damage had been done, too much bitterness and resentment to overcome.' He found that GNP+ helped them deal with such feelings by displaying their openness and commitment.

It was decided to test the reactions to the partnership by organising two or three meetings involving GNP+ over a number of weeks. Time was pressing, both because of the urgent need to expand the response to the epidemic but also because the historic event of UNGASS was only three or four months away. It offered a unique opportunity to develop the partnership.

Stuart Flavell, who had replaced Joseph Scheich as International Coordinator of GNP+, visited Geneva in 2001 for individual meetings with each of the senior managers. He recalls that some of these were 'awkward'. Didier Cherpitel, then the Secretary General of the International Federation, was worried in the beginning that the Movement would be 'used' or 'abused' because

of its emblems and reputation. But discussions with Flavell, and later staff and volunteers of National Societies who were HIV positive, reassured him.

Bermejo had to use his credibility within the Secretariat to convince senior management that GNP+ could be trusted, that they would take a mature attitude and not try to change the Federation into an activist movement. So Bermejo and Schmale persuaded senior management that the next 'test' should be to go 'slightly public' with the partnership, in a briefing of permanent heads of mission in Geneva. So on May 8 (World Red Cross Day) – only six weeks before UNGASS - Cherpitel and Flavell led the day's programme, on HIV/AIDS and working with PLWHA. It went well. Flavell presented himself well to these representatives of the international community, the Federation was in no way diminished by appearing on the same 'platform' with AIDS activists.

The success of this 'test' persuaded the Federation's senior managers to agree to take the risk of holding a joint civil society event at UNGASS with GNP+. Bermejo had involved Bernard Gardiner in the preparations for the UNGASS event, as well as the initial phases of the partnership project, and he made clear that Gardiner's brief was to work for and with both the Federation and GNP+. This involved pushing inside the Federation for equal space for the partnership; for example, he argued for quotes from GNP+ to be included in press releases about the UNGASS side event, and ensured that the Federation and GNP+ co-chaired the event. Gardiner succeeded in this despite some opposition within the Federation, linked to the general fears about the project. He explained that the concept of such a partnership was quite unusual for many Federation people and that for some it felt like 'signing a blank cheque.'

## United Nations General Assembly Special Session on HIV/AIDS

By the time of UNGASS on HIV/AIDS, the Federation was scaling up its work on HIV/AIDS. It certainly made its presence known in New York, and not just through the satellite event on the partnership. But at the same time, as permanent observers in the UN General Assembly, the Federation was also repeatedly reminded that many National Societies were yet to respond to the wake up call.<sup>1</sup>

However, many countries, such as Cambodia and Laos, included the National Societies in their government delegations to UNGASS on HIV/AIDS. The Federation's permanent observer chair was always filled and governments were effectively lobbied to include specific recognition of the volunteers of the Federation in the UNGASS on HIV/AIDS 2001 Declaration. The Federation is the only civil society organisation mentioned by name in that Declaration of Commitments.

Several of the National Societies' delegations included people living with HIV/AIDS and they took part in the Opening Ceremony. Josephine Chiturumani of the Zimbabwe Red Cross Society was tracked throughout the UNGASS by CNN. David Mukasa from the Uganda Red Cross Society represented the Federation at a side-event organised by Help Age International; and subsequently was booked for days of media interviews.

At the Federation GNP+ side event, when the floor was open to the audience, a number of people strongly criticised the Federation for its failings, and cited examples of discrimination against PLWHA by National Societies. Flavell: 'Some of it was very controversial, and not pleasant for the Federation's members present.' The response from Federation delegates was frank and honest; the failings were acknowledged, the Movement is not perfect but is now facing up to the change required by HIV/AIDS within the organisation. Such openness and the support shown to PLWHA

<sup>1</sup> Article by Bernard Gardiner in Regional Health newsletter of the Red Cross and Red Crescent Societies in East and South East Asia Region, August 2001.

were welcomed by the audience. A number of participants, including the co-chair from GNP+ (Javier Hourcade, when he was still a GNP+ board member but who since February 2003 has been working for the International Federation as HIV/AIDS anti-stigma Campaign Manager) explained that the event was for them a happy homecoming, 'as they had been involved in the Movement earlier in their life and never dreamed that HIV/AIDS would bring them back into that family.'

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***'Following the 2001 UNGASS on HIV/AIDS, it is clear that the Federation will be playing a key role wherever there is an effective response to HIV/AIDS. Partnership with people living with HIV/AIDS will be a cornerstone of the Federation's contribution. Our representatives at this UNGASS showed the Federation at its finest, but now we have commitments and expectations to live up to, and a lot of work to do to set even our own house in order.'***

Bernard Gardiner in the Regional Health Newsletter,  
Red Cross and Red Crescent Societies in East and South East Asia

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The then President of the Federation, Dr Astrid Heiberg, made a speech to the UNGASS on HIV/AIDS. She spoke of the vital importance of working in partnership with PLWHA. 'If we do not all admit to living with the virus in a deep and personal way then the development of vaccines, access to treatment, and further investment in prevention programmes will all be rendered ineffective. For it is now clear – 20 years after the virus was first identified – that the stigma and discrimination associated with PLWHA is itself one of the obstacles to preventing the spread of the virus.'

The Federation is trying to become a better home for our own staff and volunteers who are living with the virus. Their actual numbers are estimated at 200,000 or more but the reality is that all of us in the Movement – some 100 million members and volunteers – are living alongside, and with, the virus and that it is a central priority for the Federation as we face into the 21st century.'

She continued: 'They are inspiring people. We hope that their humanity, and the humanity of all people living with HIV/AIDS, will be recognised at the Special Session and in this way the world will take another step towards eliminating the stigma and discrimination associated with the virus.'

This was indeed a rallying call for the whole International Red Cross and Red Crescent Movement, to work with and involve PLWHA, as well as another very public declaration of intent to work in partnership with GNP+.

In fact, no formal agreement had yet been made, and the partnership had not been discussed at GNP+ board level. So a month after UNGASS, Alvaro Bermejo addressed the GNP+ board about the partnership. There were many questions and inevitably some scepticism, but very little opposition. As at UNGASS, Bermejo was honest about what was wrong in the past and about the Federation's limitations. Julian Hows, a member of the board, said this was 'very heart-warming.' The partnership was unanimously agreed. Hows recalled: 'They – the Federation – talked the talk, but would they walk the talk? We decided yes they would and they could.'

Flavell, GNP+ International Coordinator, has commented that in many ways this agreement to partnership was a greater risk for GNP+. Their credibility was on the line, and they perhaps risked being taken over by the much larger Federation. As he said, they didn't need the partnership to legitimise them. So why was GNP+ willing to take the risk?

## The added value of the partnership: the GNP+ perspective

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**Julian Hows: ‘They give people blankets, don’t they? So where’s the fit?’**

### GNP+ structure/work

GNP+ is a global network for and of people living with HIV/AIDS, a network of regional networks and of individuals, and a vital information resource. Its overall aim is to improve the quality of life of people living with HIV/AIDS. GNP+ started in 1986, the idea conceived by an HIV specialist nurse called Dietmar Bolle. He was HIV positive and his aim was to provide a means of empowering people living with HIV/AIDS and to help them share their personal experiences. At that time, until 1992, the network was known as the International Steering Committee of People with HIV/AIDS and its focus was the organisation of international conferences for people living with HIV/AIDS.

GNP+ still co-organises the International Conferences for PLWHA and the International AIDS Conferences (both take place every two years), but its work has expanded into other areas – advocacy, capacity building and communication. It has a membership of about 100,000 from all over the world. The central secretariat is in Amsterdam, with a staff of four, and there are affiliated networks in Africa (NAP+), Asia/Pacific (APN+), Caribbean (CRN+), Europe (ENP+), Latin America (REDLA+) and North America (GNP+ NA). Each network has its own projects and priorities and together are seen as the ‘cornerstone’ of what GNP+ is trying to achieve. Representatives from each network sit on the board of GNP+. (So it too is a federation but on a much smaller scale.)

The organisation’s Global Advocacy Agenda is the policy platform that guides its advocacy work. Key areas are promoting global access to HIV/AIDS care and treatment; combating stigma and discrimination, and creating opportunities for the voice of PLWHA to be heard in policy and decision-making that affects their lives and their communities. GNP+ has been represented on the Programme Coordinating Board of UNAIDS.

### Positive Development manual

In the area of capacity building, GNP+ provides resources, information, training and empowerment to PLWHA. Its publication, Positive Development, is a highly acclaimed manual for grassroots organisation and training. UNAIDS and the Federation both provided funding for additional translation and publication to extend its global reach. Positive Development grew out of a training workshop in South Africa in 1997, where a team from GNP+ worked with a group of HIV-positive people to develop and enhance their skills to become the ‘face’ of HIV within the national AIDS programme. The training manual was then in its infancy. Over a year, further development and research led to the final product that is seen as a vital tool for groups and individuals worldwide. It reflects the experiences, thoughts and feelings of PLWHA all over the world. It is meant to be used as a tool by support and self-help groups to promote the concept of Positive Living, and by groups that are educating, campaigning or lobbying for the rights of PLWHA. It contains information on many areas of HIV/AIDS, suggestions for activities and training exercises as well as very practical checklists and case studies from around the world.

Through its communication work, linking PLWHA through conferences, workshops, website and suchlike, GNP+ helps to strengthen and empower people. It provides, to quote board member Julian Hows, a safe and open venue to discuss issues and to learn from each other. Its mentoring work identifies activists who are then encouraged and trained by others already active in the HIV/AIDS movement.

GNP+ members also work to share their unique expertise as PLWHA with all those people involved in their care, treatment and struggle.

When the GNP+ board discussed the partnership, there were several concerns: that it might be tokenism, that, as Hows explained, it might be another ‘checkbox’ for the Federation, and that it might be an extra burden for GNP+ which has limited resources. ‘We didn’t want to let anyone down’, said Hows. But on balance, the members were positive.

### So what are the advantages of the partnership to GNP+?

First, it should help with building capacity on many different levels. GNP+ is a very young network and one that, not surprisingly, is constrained in its work by limited financial and human resources. Although the Federation cannot be expected to provide much direct funding, it should open doors to other donors – bilaterals, multilaterals and governments, the new Global Fund for AIDS, TB and malaria – and offer support and advice on fund-raising.

Michael Angaga of NAP+ explained that the partnership came at the very moment when his organization was planning to scale up but was not sure how to do this.

‘We don’t have a strong structure,’ said Javier Hourcade, former board member of GNP+ and now Manager of the Federation’s anti-stigma Campaign.’ A lot of PLWHA have nowhere to meet and no facilities like a fax machine. At GNP+ we cannot provide those facilities. The partnership should help with that.’

GNP+ networks have limited outreach. Most of their members live in cities and have no contact with PLWHA in rural areas, for example. The Red Cross and Red Crescent Movement, on the other hand, reaches out to all levels of society, including displaced people such as refugees. ‘Red Cross Red Crescent volunteers are from the real world, they reflect its diversity,’ explained Hourcade. ‘GNP+ needs to build a bridge between the international level, the clout achieved there, and the grassroots, the real world.’ By reaching out to a wider constituency, GNP+ can build up its membership and the next much needed generation of activists and leaders.



Javier Hourcade speaks with Red Cross youth in Argentina on World AIDS Day 2002.

Through the Federation, GNP+ and people living with HIV/AIDS around the world should find that many doors are opened to them. Not just the grassroots levels of National Societies

and their branches, but also the decision makers, particularly governments to whom National Societies are very close. The partnership should provide GNP+ with a platform from which to speak to governments. Together, GNP+ and the Federation can be a powerful force in advocating for comprehensive policies for prevention, care and treatment.

Individuals living with HIV/AIDS also need skills development if they are to be effective in their work. Again GNP+ is limited in the training it can offer but hoped that through the partnership, more would be offered. Stu Flavell, the International Coordinator of GNP+, said he believed the partnership would ‘transform us, make us think in a more multidisciplinary way, and position us more effectively strategically.’

GNP+ members also hoped that the partnership would eventually lead to increasing people’s access to care and treatment, especially antiretroviral therapy. They noted the good work National Societies were doing in grassroots care – often the only people doing that work, in fact – and also saw the Federation’s partnership with other organisations working on immunisation and TB as setting a precedent for HIV/AIDS.

A core aim of the partnership is to combat the stigma and discrimination from which so many PLWHA suffer. It was agreed that if the Federation – internationally, nationally and at branch level – tackled this major challenge, the effect could be startling. It offers much greater visibility for PLWHA. The Movement’s volunteers come from all levels of society and can thus spread the message of non-discrimination most effectively. Many young people are volunteers, and by linking with networks of PLWHA, they will learn at an early age about the realities of living with HIV/AIDS and become more open to the issues of marginalised people such as sex workers and injecting drug users.

Put simply, said Flavell, we’ve now ‘got someone big on our side. For me the partnership is all about creating a supportive environment for people living with HIV/AIDS.’

Strengthening the ability of the Federation to tackle HIV/AIDS is seen by GNP+ as hugely important in providing this supportive environment.



Christopher Black/International Federation

Ernest Strazdins of European Network of PLWHA and Latvia Red Cross, Lynette Lowndes, Head of the Federation Secretariat’s Europe Department, and Alvaro Bermejo advocate for anti-stigma work in 2002.

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***‘If the world’s largest humanitarian organisation cannot make a difference, then who can?’***

Alvaro Bermejo

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# The need for the partnership: the Federation perspective

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## The structure of the International Federation

The International Federation of Red Cross and Red Crescent Societies is an international humanitarian organization with a unique worldwide network. Its mission is to 'improve the situation of the world's most vulnerable people. It provides assistance without discrimination as to nationality, race, religious beliefs, class or political opinion.' Founded in 1919, the International Federation has a presence in almost every country of the world; it consists of 179 National Societies with millions of members and volunteers, and about 300,000 staff, and the Federation Secretariat with its HQ in Geneva and delegations in various regions.

The Federation Secretariat in Geneva serves as the organization's 'architect of cooperation'. and organ of coordination. It represents National Societies in the international field and helps them plan and implement long-term development programmes, disaster preparedness and many other humanitarian activities including community-based health care.

The Red Cross and Red Crescent Movement had been working on HIV/AIDS since the early days of the epidemic, but by early 2000 members of staff in the Secretariat were aware of, and very concerned about, the limited scale of this work. HIV/AIDS was the major humanitarian disaster in most of the developing world yet the world's leading humanitarian organisation was not responding on the scale, or with the urgency, that was needed.

Not only were many National Societies doing little in the face of this major emergency, but too many were also showing blatant discrimination against PLWHA. For example, one National Society refused to carry PLWHA in ambulances and opposed condom use. In another, the leadership stopped volunteers disseminating information about HIV/AIDS. But 'the Movement is about inclusion, about providing practical humanitarian assistance to those who are sick and vulnerable,' explained Bernard Gardiner, Manager, HIV/AIDS Global programme at the Federation. 'As in war, we shouldn't be asking which side are you on? The Movement must be a place that lives its values.'

The HIV/AIDS epidemic is a challenge to the whole Red Cross and Red Crescent Movement. Its major impact on countries' economies and social structures is destroying the fruits of development for which governments, NGOs and the Federation have worked hard. In Southern Africa particularly, the epidemic is contributing in a major way to food insecurity, and exacerbating the effects of poverty and inequality.

The HIV/AIDS epidemic is affecting the Red Cross and Red Crescent Movement from within. 'The Red Cross has AIDS, We have AIDS,' was a phrase used by many staff members. Volunteers, including board members, and staff in many countries are HIV+. No - one knows exactly how many but an estimate, based on the global statistics of HIV/AIDS, is 200,000 volunteers and staff (Bongai Mundeta quoted on Red Cross Red Crescent website re. Volunteers addressing General Assembly). But many have been unwilling to disclose their HIV status because of the stigma and discrimination they feared might confront them. In some countries, the high rates of sickness and mortality from AIDS are eroding the volunteer base of National Societies.

The Federation's work on HIV/AIDS had started well in the 1980s, the early days of the epidemic. It was pioneering in the way that it promoted its humanitarian Principles, advocating work with PLWHA and combating stigma.

In 1987, the General Assembly (the supreme governing body of the Federation) passed a Resolution calling on all National Societies to respond to the challenge of AIDS. Then (according to an interview with Pär Stenbäck, Secretary General of the League of the Red Cross and Red Crescent Societies in a 1990 Federation Media Pack) the 'work really took off', both at the Geneva Secretariat and in National Societies. The Federation's AIDS Programme was established in 1988. At the beginning of 1990, at least 100 National Societies were actively working in prevention and care, depending on local circumstances. Geneva supported them in a number of ways – providing information, and training materials, and organizing workshops. The former head of the Blood Programme at the League of the Red Cross and Red Crescent Societies, Dr Tony Britten, felt comfortable enough to disclose his HIV status and to be interviewed about this for the 1990 Media Pack.

A Rapid Desk review of HIV/AIDS Programmes, carried out in 2001, stated that 1990 witnessed an important evolution in the Federation's AIDS policy, with a change of emphasis towards working hand-in-hand with PLWHA.

There was a clear mandate from the General Assembly to prevent discrimination against PLWHA and to offer humanitarian support to them, their families and their friends. In response, the Secretariat created a workplace policy on HIV/AIDS - the first international organisation in Geneva to do this – and it was also the first international organisation to announce its withdrawal from the Sixth International Conference in June 1990 HIV/AIDS in San Francisco because of discriminatory US visa regulations.

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***'As a humanitarian organisation I think we will have to increase our emphasis on support and care for PLWHA and their communities, while continuing to stress prevention within our existing programmes. ...And of course we must continue our stand against the AIDS-related discrimination which is growing in some areas of the world.'***

***'People with AIDS have taught us that living with any disease or disaster is not only a matter of the body but of the mind and spirit. In our humanitarian efforts in the years to come, this is a lesson we will not forget.'***

Pär Stenbäck, 1990 Media Pack.

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Good work on HIV/AIDS continued in many National Societies – youth peer education programmes, home-based care in, for example, Zimbabwe, often carried out by HIV+ volunteers. Jamaican Red Cross (with the support of the American Red Cross) and Nepal Red Cross ran HIV prevention programmes. HIV/AIDS was the key international programme of the Australian Red Cross, and it supported programmes in Cambodia, China, Laos, Myanmar and Vietnam. Through the French Red Cross, clinics providing treatment for HIV/AIDS were established in various parts of West Africa. The Thai Red Cross was at the forefront of HIV/AIDS work in Thailand; it opposed the government's plans for mandatory testing and a register of names, carried out excellent advocacy and ran programmes to prevent Mother To Child Transmission of HIV. It was also involved in clinical trials of treatment.

But, having been at the forefront of HIV/AIDS activities in many places, and in its work on discrimination against PLWHA, the Federation lost the momentum and in the mid-90s it reduced its activities and support to HIV programming as many international humanitarian organisations shifted focus to the Great Lakes and later to the conflicts in the Balkans. This may have been due to a reduction in available resources or the restructuring of the Federation Secretariat.

Looking back to that period of the mid 90s onwards, a Rapid Desk Review of HIV/AIDS Policies, Strategies and Programmes of the Federation, March 2001, highlighted several major weaknesses including the fact that:

- The Federation had not been particularly effective in practising non-discrimination. ‘It is observed that there has been more “talk than walk” at all levels of the Federation’s structure.’ ‘Programmes assist the PLWHA to cope with injustices but do not advocate for their rights.’
- The power of the well - respected Movement’s emblems had not been harnessed to (fuel effective) advocacy and education. Thus inadequate use of the emblems in this regard is a missed opportunity.
- The lack of monitoring and evaluation systems meant there had been a missed opportunity to institutionalise and build on the use of AIDS experience from the vast Federation network. Thus the fact that programmes were too small to have any real impact on the epidemic was not identified.
- There had not been enough sharing and dissemination of experiences nor encouragement to National Societies to develop and scale up their work.
- Some National Societies had resisted recognising the seriousness of the problem of HIV/AIDS. Few had taken advantage of participating in high level National AIDS committees, because they were not visibly involved in the work in their own countries.

In early 2000, by which time almost 25 million men, women and children in Africa were infected (34.3 million people worldwide) there was a growing feeling among experienced staff, inside and outside the health department, that something dramatic needed to be done to encourage a radical change in the Federation’s response to the epidemic. A voluntary group came together with Alvaro Bermejo, the new head of the health department, to develop a strategy for scaling up the organisation’s response.

One early, concrete result of these meetings was a ground-breaking video called “Living with...”, funded by staff members, that included moving personal testimonials from Federation staff and volunteers who were living with HIV/AIDS. It was part of the effort to make the Federation ‘a better home for people living with HIV/AIDS’.

Thus, when the idea of the partnership between the Federation and GNP+ was first broached by UNAIDS’ Calle Almedal in 2000, it fell on fertile ground.

Furthermore, in 2000, the Pan-African National Societies Conference (strongly supported by National Societies attending from other regions) adopted the Ouagadougou Declaration which stated that National Societies in Africa commit to ‘responding to the HIV/AIDS pandemic as an unprecedented humanitarian and development disaster in Africa, by massively scaling up their response in terms of advocacy, prevention, care and mitigation.’

## Benefits of partnership for the Federation

It was clear from the start that there were many potential benefits of the partnership to the Federation. The Federation's Secretariat and National Societies urgently needed to improve their expertise in HIV/AIDS – to become more 'AIDS competent' – and to scale up their activities on prevention, care and treatment. GNP+ and its members offered unique expertise, experience, commitment – and credibility, to the Federation's activities on HIV/AIDS.

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***'The Greater Involvement of People Living with HIV/AIDS (GIPA) can reinforce an organization or activity by exposing it to the unique perspectives that PLWHAs' direct experience can bring.'***

(UNAIDS GIPA 99, p4)

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The partnership would help the Movement to fight stigma and discrimination both within the organisation and in society generally. Working with PLWHA on a daily basis, and having a name and a face to associate with the concept of a person with HIV or AIDS – where previously the association was with a virus or terrible disease – helps people overcome their fears and prejudices, and change their perceptions of PLWHA. Flavell of GNP+ said people always behave better when he is in the room. 'It stops them objectifying the disease.'

Bermejo and his colleagues were convinced that the partnership would enable them to provide a 'better home for PLWHA' inside the Movement, and a more supportive environment outside. By doing this, the Movement would be fulfilling its mandate, to improve the lives of vulnerable people by mobilizing the power of humanity. By tackling stigma and discrimination, it would enable PLWHA to lead dignified lives. The Movement would be fulfilling its mission towards humanity, carrying out the job it is mandated to do.

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***"Vulnerable people are those who are at greatest risk from situations that threaten their survival, or their capacity to live within an acceptable level of social and economic security and human dignity"***

Federation's Strategy 2010, p12

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If the partnership resulted in true participation, it would also lead to a major shift of focus, moving from the traditional 'help approach' for 'victims' to more of a 'peer approach' to equal human beings. By providing a basis for partnership, mutual respect and understanding, GIPA breaks down simplistic concepts of "service giver" (that is the person who is not HIV-positive) and "service receiver" (the person who is). (UNAIDS GIPA doc, p 4, 1999).

The partnership – with its very public launch and profile – would serve as a useful political tool internally to leverage more commitment and resources to HIV/AIDS within the organisation.

Indeed, in November 2000 (triggered by the actions of the group of staff in Geneva and a newly created dynamic HIV/AIDS Governance Group) the Governing Board approved a position paper on advocacy on HIV/AIDS, and in the same month the Steering Committee adopted the following decisions:

- To make HIV/AIDS an institutional priority
- To implement peer senior management education

- To create a cross-divisional task force
- To request that departments work towards having HIV/AIDS included in all relevant policy by the General Assembly in 2001.
- To include all HIV/AIDS considerations in all emergency appeals for countries where the prevalence is more than 1% in 15-49 year olds.<sup>2</sup>

So almost simultaneously, the foundations for the partnership with GNP+ and for the Federation's future work on HIV/AIDS were laid down.

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*'The very meaning and interpretation of the Principle of humanity has been affected for the better by this partnership which was just waiting to happen once the discontent at our own performance could no longer be contained.'*

Denis McClean, Head, Media Service, International Federation

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### Using the partnership for 'internal' advocacy: the meeting of the IFRC General Assembly in November 2001

The small HIV/AIDS team at the Federation Secretariat in Geneva has worked hard to harness the power of GIPA and the partnership for internal advocacy.

In November 2001, the General Assembly of the Federation, meeting in Geneva, heard from four Red Cross volunteers living with HIV/AIDS – Ramon Acevedo, Josephine Chituramani, David Mukasa, and Patinya Thakaeng. They have been 'breaking the silence' on HIV/AIDS for the last few years through their work with the Movement. The volunteers and staff, all of whom are living with the virus, spoke to the Assembly about their lives, work and attitude and received a standing ovation.

**"Working with the Uganda Red Cross Society has helped me as a person - I found out that when you have the HIV virus you are strengthened and you do not feel alone. Along the way you find others that are like you. If you don't come forward others might hide away." David Mukasa**

**"I started to work in prevention because I felt it was my responsibility to assist others through my example and testimony, to contribute in the fight against stigma and discrimination, for my daughter and for all the children of the world who deserve a better future." Ramon Acevedo**

"I would like to tell everybody that we have more than 100% strength, patience and intelligence to fight AIDS and to do many things in our community. Please give us the chance to stand with you. I know we can walk comfortably together when you know who I am," said Patinya Thakaeng of the Thai Red Cross.

Josephine Chituramani of the Zimbabwe Red Cross told the Assembly; "What one person can do is help a few, what one National Society can do is help many. What we can all do, if we make a real commitment, is to help hundreds of thousands. We must work together in prevention and care, we must fight stigma, we must pass on the truth about HIV and AIDS."

There was a very moving and poignant video shown, introduced by Bongai Mundeta, the Federation's Regional HIV/AIDS Coordinator, Southern Africa, and past Secretary

<sup>2</sup> By September 2003, these decisions had been implemented. Indeed, explained Gardiner, the task force now meets only around specific issues. It was not deemed necessary to meet on a regular basis because HIV/AIDS was much more integrated into people's work.

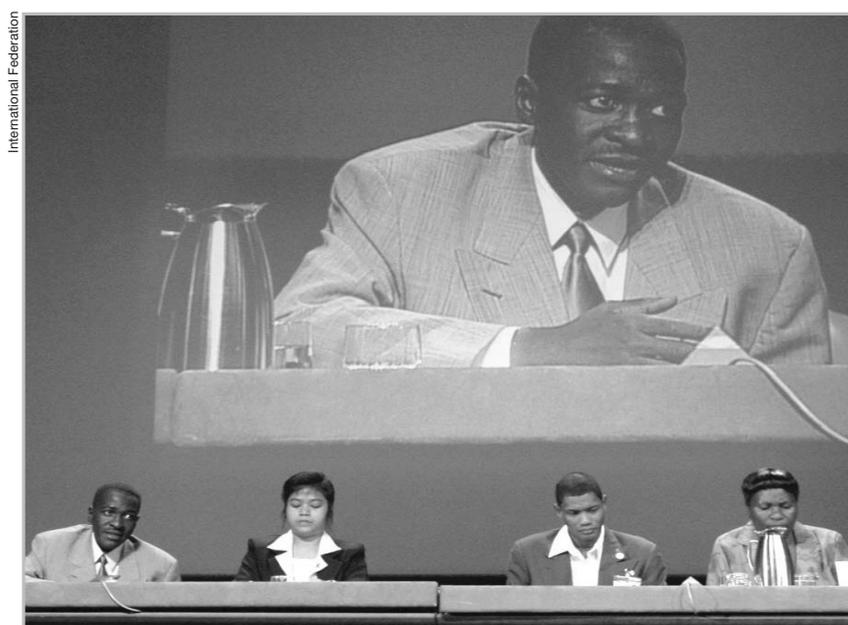
General of the Zimbabwe Red Cross. It was an interview with Masambo, a frail 40 year old woman living with AIDS, and, said Mundeta, 'one of our own.' By the time the video was shown, she had died. Mundeta explained that this woman was a pioneer. In 1992 she had joined a group of 25 volunteers in Harare, to be trained by the Zimbabwe Red Cross in providing homebased care for PLWHA. 'She continued to work as a care facilitator until she fell ill three months ago. Masambo is only one of many of our Red Cross volunteers who is infected with AIDS. For almost ten years, she made a difference in her own community - providing care for those who were shunned and forgotten by society. When we met her the last time, she still wanted to make a difference. She wanted to share with you her experience. She died four days later. We cannot and must not forget to take care of our own.'

The video brought home in an intense way the human cost of HIV/AIDS, and the cost to the Movement.

**Calle Almedal of UNAIDS, who had conceived the original idea and facilitated the partnership, said he recognised the Federation as potentially one of the most effective players in this fight. "With your global network and the most powerful emblem in the world you guys can and will make a difference".**

Flanked by HIV-positive Red Cross volunteers, the outgoing International Federation President Astrid Heiberg asked "Are we brave enough to respond? Have we the courage as an organisation and as individuals to speak out where it may be taboo? Are we committed to working with other organisations that may be different from us? Is there any real choice for the Red Cross/Red Crescent?"

Danish Red Cross President Freddy Pedersen underscored the Red Cross/Red Crescent's obligation to speak out to combat stigma and discrimination. "Silence is not an option. Silence kills. Discrimination kills. Let's be honest - what makes HIV different is the way it is transmitted. We have to discuss things that are not talked about openly: sex, blood, death, promiscuity, sex workers, drug abuse, homosexuality."



David Mukasa, Patinya Thakaeng, Ramon Acevedo and Josephine Chiturumani speak to the Federation's 2001 General Assembly.

## The development of the partnership

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After the 2001 UNGASS on HIV/AIDS, the partnership was very much at the forefront of the Federation's work on HIV/AIDS. It was fortunate that such a major event as UNGASS took place so early in the life of the partnership. UNGASS gave it high profile and placed it clearly on the agendas of leaders within the Federation, thus giving it a momentum to develop and grow.

At an international level, the UNGASS on HIV/AIDS was the first of several 'milestones' on the partnership's journey. Others were the launch of the anti-stigma campaign by the Federation and the AIDS conference in Barcelona in 2002. Lower profile, but still very important to the development of the partnership, were internal actions and events of the Federation and the involvement of GNP+ ; and World AIDS Days and World Red Cross/Red Crescent Days. All these provided opportunities to push the partnership and to grow it.

The partnership has never been 'set in stone' through a MOU or contract. Some of those involved are critical of this, arguing that they would like more coherent direction, such as a strategic framework or road map. Yet these very critics of the lack of direction are often the people who have been pioneering and visionary in the way they have perceived and developed the partnership. The informality of the agreement thus gave them space to be more creative. Gardiner explained: 'We don't have a MOU because we are perpetually pushing the boundaries of our vision, for mutual benefits. It is a risk but it's worth it.'

In May 2002, a letter was sent out to members and networks of GNP+, all National Societies and UNAIDS. It flagged up the partnership between GNP+ and the Federation, and the two anti-stigma campaigns – **The truth about AIDS. Pass it on...** and the World AIDS Campaign **Live and Let Live**. The letter encouraged 'the United Nations system at all levels and the Federation and National Red Cross/Red Crescent Societies, in partnership with GNP+ and national organizations of people living with HIV/AIDS, to collaborate in these campaigns.' It was signed by Stuart Flavell, International Coordinator, GNP+, Jean Ayoub, Director of Cooperation and Development, IFRC, and Michel Sidibe, Director, Country and Regional Support Department, UNAIDS. The letter was another public, though somewhat low key, statement – and reminder to National Societies - about the partnership.

The Federation's anti-stigma campaign – **The truth about AIDS. Pass it on...** was launched on 8 May 2002 – World Red Cross Day: This was the Federation's contribution towards the UNGASS objective to eliminate stigma and discrimination which fuel the epidemic and are major barriers to work on prevention, care and treatment.

The key concept of the campaign is that through actions, events and advocacy, the truth will spread faster than the virus, and that the fear and ignorance surrounding the virus must and will be reduced.

The campaign is a collaboration between the Federation, GNP+, UNAIDS and the advertising agency Saatchi and Saatchi. In all the publicity materials, the partnership with GNP+ is given a high profile (see box for extract from original press release) and National Societies are encouraged to 'develop their objectives and strategy in close collaboration with local groups or networks of PLWHA.'

## Federation PRESS RELEASE ON anti-stigma CAMPAIGN

### **Partnering with GNP+**

The International Red Cross Red Crescent Movement is a known and trusted organisation locally and globally, it has relatively easy access to international dialogue and decision-making, for example, with Permanent Observer Status at the United Nations and working agreements with many of its agencies, and at a national level is recognised as 'an auxiliary to the public authorities.'

One must also recognise however that its record in the sphere of HIV/AIDS programmes and advocacy has to date been relatively limited in its commitment, although more active in some countries than in others. The organisation may also be viewed or considered by some people, particularly young people, to be traditional and conservative.

The decision therefore for the Red Cross Red Crescent to partner with GNP+ (Global network of People living with HIV/AIDS) is pivotal, perhaps even inspired, and certainly crucial to the success of an anti-stigma campaign. GNP+ are committed to this cause, 24 hours, 7 days a week, 52 weeks every year by virtue of their own lives and status. They are already working to change opinions, to lobby for more respect and human rights, they are striving to improve the quality of life for PLWHA, they are the personalised face of HIV/AIDS. They are men and women from all races, all classes, all religions, across the class spectrum, from already marginalised groups to the highest levels of society.

They recognise also that the partnership between the Red Cross Red Crescent and GNP+ in an anti-stigma campaign can really make a difference, can change attitudes and policies, can allow PLWHA to live a full life and contribute to reducing the impact of the pandemic. The partnership can help to bring about a reduction in new infections, and an increase in the provision of care and in the access to drugs for PLWHA.

The partnership with GNP+ is appreciated and endorsed by UNAIDS with whom the International Federation is also working closely in the development of its programmes and the HIV/AIDS related stigma and discrimination.'

From An Overview on the Global Campaign 2001.

GNP+ participated fully in events and media coverage linked to the campaign on World Red Cross Days and World AIDS Days. For example, on World AIDS Day (December 1) 2001 Flavell, GNP+ International Coordinator, was in Argentina, appearing on TV with the Regional Head of Delegation for the Red Cross. There were several events in Latin America, organised by the Federation and the Latin American network of PLWHA, REDLA+. Flavell stressed the significance of such collaboration, at a very early stage of the partnership, and in a very conservative region.

Some people in the field are critical of the campaign . They find that it still lacks depth and local relevance at the national level, because National Societies have yet to define for themselves medium to long term objectives that they really own. So the campaign in many countries is still too often linked to events to create awareness rather than sustained programmes or projects.

## Participation of GNP+

GNP+ has been closely involved in the Federation Secretariat's policy making on HIV/AIDS, and Flavell and his colleagues have been invited to monitor the work of the Federation on HIV/AIDS.

In April 2002, Flavell was invited to participate in the Regional European Red Cross and Red Crescent Conference in Berlin. Its two main themes were health and care in the community, and migration. The aim was to determine priorities for the next four years. HIV/AIDS was a key topic for discussion, and Flavell made a presentation. He recalled that some of the participants were doubting their ability to respond to such an emergency. 'I said "you can and must do something"'.

The resulting Berlin Charter referred to 'the deprivation of the right to health to increasing numbers of vulnerable people' and stated: 'We want to ensure that those affected by HIV/AIDS, TB and other infectious diseases are able freely to access appropriate care. We want to extend our assistance and protection to all those in need of it, in accordance with international humanitarian law, human rights law, tolerance and human dignity.' They also committed themselves to sparing 'no effort to ensure that all people enjoy access to health care.'

In the European National Societies' Plan of Action on Health, they committed to developing partnerships with the European Network of People Living with HIV/AIDS (ENP+) and other organizations of PLWHA.

Every two years the Federation evaluates its work on HIV/AIDS in seven or eight countries in order to extract key lessons for the whole of the Movement. Since the early days of the partnership, members of GNP+ and its networks have been involved. Dorothy Odhiambo from NAP+ was in the evaluation team for several African countries, and Julian Hows, head of the European network, evaluated the programme in Latvia. The evaluation reports will be published. The Federation will continue to involve GNP+ in the evaluations as part of a conscious effort to build the principle of GIPA into monitoring and evaluation.

## International AIDS Conference, Barcelona

The Federation made full use of the International AIDS Conference in Barcelona, July 2002 (GNP+ was a co-organiser) to show its commitment to increasing its work on HIV/AIDS and to the partnership. It used the event to develop the leadership and technical skills of members, with a tailor made programme for the senior leadership of 50 National Societies. A major aim was to develop the understanding and competencies of leaders in the Federation for the essential role they must play in the response to the epidemic. Programme staff from National Societies had requested this of the Secretariat because many were frustrated by working under leaders who are indifferent to HIV issues, or actually block sound responses.

Leaders from National Societies were actively encouraged to promote and support the partnership with GNP+. Presidents and Secretaries - General of National Societies attending Barcelona were asked to include at least one person living with HIV/AIDS in their delegation to the conference. This 'forced many to reach out for the first time, and the result of doing this was very positive. This brought to view a whole new generation of PLWHA in the Federation, to build on the pioneering work of those who appeared in the 'Living with...' video.' Some 12 PLWHA were included in the Federation's delegation to Barcelona.



Daysi Rivera conducts a press conference in the Federation's booth at the XIV International AIDS Conference.

The President and the Secretary-General of the Federation attended. Some 60 National Societies sent delegates (mainly leaders), representatives of local PLWHA networks and National Society volunteers living with HIV/AIDS. 'This acknowledged clearly that HIV/AIDS exists within the Federation whether people like it or not,' explained Gardiner. In the afternoons, the Federation ran workshops for their delegation, parallel to the main sessions, taking advantage of the large number of experts attending and involving them in raising the awareness of Federation delegates.

The very public camaraderie between Federation leaders and PLWHA should not be under-estimated. The Secretary-General of the Federation took about 16 PLWHA to dinner, for example. Whether at an international conference or a small local event, such actions put across a strong anti-stigma message. Federation leaders had to confront their own prejudices during the conference, and at least two spoke of a major change of attitude that would lead to action.

Presentations were made by a number of PLWHA brought to Barcelona by the Federation. These included Marlene Daysi Rivera of the Honduras Red Cross and Ernest Strazdins, a young man from the Latvia Red Cross who did the whole of that National Society's presentation. Other PLWHA who work with the Federation, such as Michael Angaga and Dorothy Odhiambo, were also at the conference in their capacity as NAP+ members.

The Spanish Red Cross in Catalonia strongly supported the Federation's programme and provided 400 volunteers to help at the conference.

The results of the Federation's work on leadership development at Barcelona were not insignificant. At the end of the conference, the Federation leaders agreed on a declaration (see Annex) and this was distributed to all National Societies with a letter from the President of the Federation, Juan M. Suárez del Toro R. In this letter he wrote that HIV/AIDS will be a key issue during his term as President and stressed the importance of the partnership: 'We can ... do much to ensure the voice of people living with HIV/AIDS and their families is heard. During the conference, we also welcomed some new leaders to our fold, the Movement's delegates living with HIV/AIDS. The testimonials and humanitarian action of these delegates clearly demonstrate that they have earned their place as key partners of senior leadership in the HIV/AIDS response.'

The President made clear the imperative for the Movement to act against stigma and discrimination, recognising that the 'HIV/AIDS crisis is a profound opportunity to define much of the Red Cross Red Crescent mission for the current age.' He wrote: 'Associating with people living with HIV/AIDS and other vulnerable groups may mean we attract stigma to ourselves, but we have to be strong and live up to our humanitarian values in response. Our willingness to stand together with the vulnerable will do much to reverse the tide of ignorance, fear and inhumanity.'



Juan Manuel Suárez del Toro Rivero, Soy Bounsavath of Laos Red Cross, and Bernard Gardiner speak at the Federation's anti-stigma satellite meeting at the XIV International AIDS Conference.

He concluded: 'In the past, the Movement's leaders have responded to crisis in ways that lift the human spirit and make a lasting difference. The current HIV/AIDS crisis is equal to anything that has come before. I hope we can all rise to this challenge in ways that honour and update the legacy we have inherited, and that together we can revitalise humanitarian action and volunteerism.'

The Barcelona Declaration made specific references to partnership with PLWHA, and to ensuring their full participation in the response to the epidemic.

It was agreed that at the next Board meeting of the Federation, there would be a session involving a person living with HIV/AIDS and Peter Piot, the Executive Director of UNAIDS.

Individual commitments were also made by news leaders. The President of the Indonesian Red Cross wrote a strong advocacy paper for a national paper in Indonesia. He made it clear to senior staff of the National Society that a strong HIV response must be a priority.



Christopher Black/International Federation  
Stu Flavell, Didier Cherpitel and Mathieu Kalombo of Red Cross of the Democratic Republic of the Congo in Barcelona.

The President of the Uganda Red Cross Society offered the support of his National Society for the next International Conference of PLWHA, to be held in Uganda in the autumn of 2003.

There was a strong belief that without the partnership and thus the involvement of so many PLWHA in the Federation's delegation, much less would have been achieved at the Barcelona conference in terms of the Federation's response. The participation of the PLWHA also, as Patrick Couteau, the Regional HIV/AIDS Coordinator in the Red Cross Red Crescent Regional Delegation Nairobi said, animated, gave life to the partnership. The Barcelona was a major milestone in the development of the partnership.

The efforts of the Federation were also recognised at the GNP+ side-event. A representative group from the Federation delegation attended; Flavell of GNP+ named each one, and he talked of the Federation as a partner that 'has "walked the talk" in the last year. The assembled PLWHA from around the world cheered and clapped the Federation for minutes.'

A key issue at the conference was access to treatment, and a number of leaders asked the Secretariat of the Federation to 'do something'. This debate would rumble on (see below), a potential stumbling block for the partnership. Issues raised included:

- Should the Secretariat 'order' National Societies to make treatment available to all staff and volunteers living with HIV/AIDS?
- If not, how can National Societies be persuaded to do this?
- Can National Societies be involved in the delivery of antiretroviral therapy, especially in resource-poor settings? And if so, with which partners?

## Changes in Federation policy on HIV/AIDS

From early 2001, and then spurred on by UNGASS, the Federation made a major effort to scale up its work on HIV/AIDS. In 2002, the Federation updated its policy on HIV/AIDS. In this document, it noted 'the close relationship between health and human rights and the importance of involving PLWHA in the fight against AIDS.'

The partnership with GNP+ is seen as key to the Federation's plans for organisational change, at all levels, and to promoting a more effective response to the epidemic. In November 2001 the General Assembly made another resolution on HIV/AIDS and announced its decision to scale up the response.

Bernard Gardiner, Manager of the Global HIV/AIDS Programme at the Secretariat, said that the difference between the Federation's work now on HIV/AIDS and its earlier, quite pioneering work in the 1980s/early 90s that faltered, is the effect of the partnership. 'Now we have GIPA, through the partnership with GNP+, and through this too we are stressing the importance of our humanitarian Principles.'

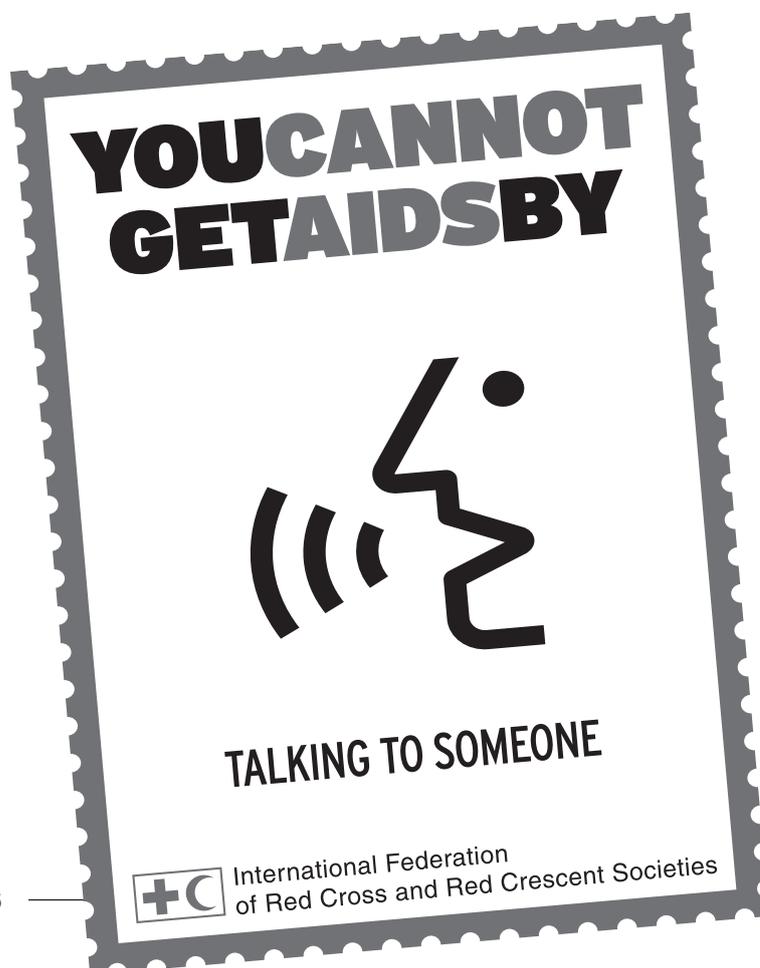
In January 2003, the Federation produced a revised HIV/AIDS in the Workplace Directive. In his letter announcing the new directive, the Secretary General Didier Cherpitel wrote: 'A supportive and compassionate workplace can enhance the control and prevention of HIV/AIDS, and mitigation of its impact. But more importantly, it contributes to protecting human dignity... The management of the Federation is determined to take the necessary measures to make the Secretariat, both in Geneva and in our field delegations, a better home for PLWHA... Together, we can create a supportive and compassionate workplace through our actions.'

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***'Why would activist organizations want to be associated with dinosaurs like the Red Cross?'***

Julian Hows, GNP+ board member, at the 14th International Harm Reduction Conference, Chaing Mai, 2003

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## Partnership in regions and countries

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National Societies have been strongly encouraged by the Federation's Secretariat in Geneva to work in partnership with PLWHA networks. But the rate at which they have developed a local partnership has been very variable, for a number of reasons; limited resources, fears and anxieties about such a different way of working (for some, that is), within fairly traditional societies.

The leadership acknowledges these difficulties. 'I am very proud of our partnership with GNP+, ' said Didier Cherpitel, Secretary-general of the IFRC from January 2000 until June 2003. 'We had not done much before, it 's very difficult to walk the talk.' He acknowledged the strong leadership from within the Red Cross Red Crescent in some countries. 'It is not easy to take a position on discrimination within your own country. You have to have guts, no ego, no personal agenda.' He pointed to the need to tackle societies' governance on the HIV/AIDS issue, and stressed the importance of persuading key individuals, such as the Presidents, in National Societies.

### A regional overview

In some countries – for example, Zimbabwe, and Thailand - National Societies had been working with PLWHA for some years, as volunteers providing home-based care and in other capacities.

In all regions, there is some discourse between PLWHA and the Red Cross Red Crescent Movement, if only at the occasional workshop or through working together on events for World AIDS Day. The anti-stigma campaign has provided a useful catalyst for stimulating partnership.

**Africa:** The Regional Delegation in Nairobi (East Africa) was visited for this case study, because it has achieved most so far. The writer also attended a workshop where the Southern African National Societies came together to share their thinking and activities on HIV/AIDS. There are considerable differences between National Societies in developing the partnership, but there is a clear determination from the Regional Delegation in Harare to make the partnership work.

**Middle East and North Africa:** The Moroccan Red Crescent is partnering with local NGOs, groups involved with and supporting PLWHA and the government's National programme against HIV and AIDS.

**Caribbean and Latin America:** There is a good level of partnership in a small number of countries: Bolivia, Dominican Republic, Honduras and Jamaica. The National Societies offer support to PLWHA organisations, and they organise activities together. In a second group, they come together occasionally – on World AIDS Day, for example, and a third group are doing nothing, a combination probably of traditional National Societies and weak PLWHA networks. Honduras was chosen for this case study because it has, along with the Dominican Republic, been more active in partnership with PLWHA networks.

In **Asia and the Pacific**, there are also great variations. The PLWHA movement is weak in many Asian countries but as in other regions, some National Societies have been working with PLWHA – as organisations or individuals – in HIV/AIDS activities. A prime example is the Thai Red Cross which has played an important part in the country's suc-

cessful political and social mobilization against the epidemic. Its Wednesday Friends Club, which was set up in 1990, is an important support group for PLWHA. The Asian Red Cross and Red Crescent AIDS Task Force which was set up in 1994 to serve as a platform for National Societies for cooperation, coordination and knowledge sharing, works on developing partnerships with networks of PLWHA.

A number of HIV/AIDS programmes run by National Societies in Asia and the Pacific will benefit from funds from the OPEC Fund for International Development. Part of the agreement involves the training and participation of PLWHA, as well as developing the anti-stigma campaign.

A practical result of the partnership is that in July 2003 APN+ moved into the Australian Red Cross sub-office situated within offices of the Red Cross/Red Crescent Regional Delegation in Bangkok.

**Eastern Europe:** The partnership has mainly focused on technical support being given to National Societies by the European Network of People Living with HIV/AIDS (ENP+). This includes training workshops on stigma and discrimination for the Youth Section of the European Regional Network on AIDS (ERNA), founded by 12 European National Societies as a forum to deal with HIV/AIDS. GNP+'s manual *Positive Development* has been translated into several languages.

Even where there is an openness and willingness on the part of the Federation to work in partnership, there is not always an organisation or network of PLWHA capable of partnering. This is particularly marked in countries where stigma and discrimination are widespread and thus people risk a great deal to reveal their status. There are also limited resources within the Federation, with very few staff specifically dedicated to work on HIV/AIDS at any level or in National Societies.

## East Africa

**The Regional Delegation Nairobi (RDN)** was chosen for this case study because it is the first region of the Federation to put into operation a clear strategy and programme for the partnership between itself and the Network of African people living with HIV/AIDS (NAP+). The Region covers 14 countries: Burundi, Comoros, Djibouti, Eritrea, Ethiopia, Kenya, Madagascar, Mauritius, Rwanda, Seychelles, Somali, Sudan, Tanzania and Uganda.

### The challenge

At the annual partnership meeting of the Regional Delegation of the Red Cross/Red Crescent for East Africa, The Horn, Great Lakes and Indian Ocean islands, in June 2001, leaders from the region's National Societies confronted the urgent need to scale up their HIV and AIDS prevention and care interventions. They asked the RDN to help them in facing the unprecedented disaster of the epidemic.

The challenge was – and still is - enormous. Kenya, Djibouti, Burundi and Rwanda are among the 15 countries in the world with the highest adult HIV prevalence. In most of the region, life expectancy is decreasing. The East African region has almost five million children orphaned by AIDS ; in Kenya alone, the epidemic is expected to leave one million children orphaned by the end of 2003. Conflicts in some countries are further fuelling the epidemic as people are displaced and forced to live in refugee camps.

Although all the National Societies in the Region were at this time running some HIV/AIDS activities, they were only on a small scale. A number conducted prevention programmes, disseminating information and, in some cases, condoms. Others had programmes for the home-based care of people living with HIV/AIDS and a few had started programmes to support orphans.

Most significantly, it was recognised that ‘the virus has already entered into our Red Cross/Red Crescent branches and volunteer networks, threatening to destroy the National Societies’ human resources base too.’ Thus, continued the Appeal and Action Plan, East Africa RDN, Regional HIV/AIDS Programme, 2002, ‘HIV/AIDS programme development is a fundamental prerequisite to any current or future sustainable Red Cross/Red Crescent development intervention. If not, most of our investment in developing the capacities and services of the National Societies to reach the most vulnerable are going to be lost.’

### Partnership is key to meeting the challenge

The RDN had just appointed Patrick Couteau as Regional HIV/AIDS Coordinator, and he arrived in July 2001, one month after this meeting. Although most of his career has been spent with the Federation, he had worked at UNAIDS for five years. There his responsibilities for liaison with NGOs included working with GNP+ on the development and publication of the manual *Positive Development*. Just before taking up his post in Nairobi, Couteau had attended the official launch in Geneva of the partnership between the Federation and GNP+. He recognised its potential for developing and implementing the principle of GIPA, and was keen to turn the vision into reality. He wanted to ensure that the partnership really did mean ‘added value’ for PLWHA.

But putting into operation the partnership with GNP+ was a considerable challenge. The African networks of PLWHA were not in good shape and massively under-resourced. Couteau and his colleagues were concerned that the partnership, once established, must ‘go beyond declaration of intention and information sharing to joint planning and resourcing.’

The first step, in August 2001, was to establish an agreement to operationalise the partnership between NAP+ and the Regional Delegation Nairobi. The objectives of the partnership were set out as follows:

- To enhance the partnership between National Societies and GNP+ together with its regional networks such as NAP+ to address the issue of stigma and discrimination
- To empower the disadvantaged and marginalized PLWHA at the community level in the Region in partnership with NAP+
- To increase visibility and strengthen the contribution of PLWHA in the fight against the epidemic <sup>3</sup>

The beneficiaries would be :

- PLWHA at grassroots level in the overall region
- National and community-based associations of PLWHA
- The Red Cross and Red Crescent National Societies
- The National HIV/AIDS programmes, to help them focus on the greater involvement of PLWHA <sup>4</sup>

The opportunities and challenges identified by the two partners were how to use the Federation as a platform, partner and vehicle to ensure that millions of people who are already HIV positive or have AIDS and who are out of reach of NAP+ and most national associations of

<sup>3</sup> RDN Best Practice briefing on the partnership.

<sup>4</sup> *ibid.*

PLWHA, can have access to comprehensive care including affordable drugs and to ensure that they live full and productive lives in their communities. (ibid)

**(Patrick Couteau's Appeal 2002): 'History will not forgive us if we stand by and watch the tragedy unfolding without acting sufficiently. We will look back in shame that millions of fellow humans were dying and we only reacted by talking about it and implementing small scale projects...while the National Societies as auxiliaries to governments are probably the most decentralized, structured and community-based organisations through their network of branches and volunteers all over Africa. By mobilising this unique comparative advantage and in partnership with others we can certainly make a difference, contribute to save the lives of thousands of fellow humans and alleviate the suffering of the many individuals, families and communities currently devastated by the killer virus.'**

There was not surprisingly some initial scepticism at NAP+ about the idea of the partnership. The Federation is a very traditional organisation that is close to government and neutral, or non-confrontational, towards governmental policy and attitudes. NAP+, on the other hand, is by its very essence an activist organisation that confronts and questions governments. However, Michael Angaga, the NAP+ Coordinator and co-founder, and Dorothy Odhiambo, a founder member and advisor to the network, could also see the potential of the partnership for PLWHA and the network. NAP+ wanted to scale up the visibility of PLWHA through its programmes but had very limited resources to do this. It was also clear that such a partnership could provide more support to home-based care programmes in the community and, through the National Society's branches, empower PLWHA to develop support groups.

An action plan for the partnership was developed and agreed. It was clear to Couteau that the development of the partnership should begin within the RDN. Once it was shown to be feasible 'in house', National Societies could be encouraged and persuaded to follow suit – with support from the RDN.

From the beginning, there was a clear vision of what the partnership could offer, and how it could be operationalised. It has been carefully and meticulously planned, thought through and well documented. 'I simply wanted to take those nice words written in guidelines and policies and turn them into reality,' said Couteau.

The first steps in setting up an effective partnership were:

- To recruit a PLWHA partnership officer to work with the HIV/AIDS Coordinator in the Regional Delegation, Nairobi
- To establish a HIV/AIDS workplace programme in the RDN first, and then to promote this model throughout the National Societies, so as to provide an environment where PLWHA feel safe and supported and where HIV/AIDS issues can be freely discussed
- Training initiatives to build up the capacities of both organisations – the Federation and NAP+ - in advocacy and networking

### Recruiting a regional PLWHA partnership officer

One of the first, and most important, steps in operationalising the partnership was to recruit a Regional PLWHA Partnership Officer. The main responsibility was developing the partnership, 'in order to promote a meaningful involvement of PLWHA in Red Cross/Red Crescent

interventions'. This included:

- Assisting Red Cross/Red Crescent organisations and national networks of PLWHA in implementing a two year anti-stigma campaign
- Assisting in building the capacities of National Societies and PLWHA organisations in networking and advocacy
- Providing technical guidance to both organisations on how to involve and empower PLWHA to participate in the design, implementation and evaluation of the Federation's HIV/AIDS prevention and care programmes
- Contributing to Regional/National training initiatives to empower PLWHA
- Assisting in the development and implementation of HIV/AIDS policy and workplace programmes for the Federation's staff and volunteers

The advert certainly caught people's attention. It carried the emblems of both organisations and called for applicants to be persons living with HIV/AIDS. Some people assumed it was a mistake, maybe a printing error. Many others sent messages of congratulations. The advert alone gave good visibility to the partnership.

Dorothy Odhiambo was recruited in June 2002. She is a well-known and highly respected activist and member of NAP+ in Kenya. She was diagnosed HIV+ in 1989 when she was a teacher and mother of a young child. She had been a member of the Programme Coordinating Board of UNAIDS. Though her salary is paid in full by the RDN, Odhiambo was hired to work 50% for both organisations, as Senior HIV/AIDS Partnership Officer for the RDN and as Advisor to NAP+ (where she had been working as a volunteer). In a sense, Odhiambo is the embodiment of the partnership, working for both organisations. She has brought considerable experience and expertise to the post, able to communicate and work at every level, from small communities to government ministers.

Couteau explained that only someone who is HIV positive can talk on behalf of PLWHA. 'They have a unique personal viewpoint and this cannot be learned from books. If I am to translate the concept of the partnership into practical action, I cannot do this without working closely with someone living with HIV/AIDS.' And importantly, 'donors listen to her.'

## Setting up an HIV/AIDS Workplace programme

**Couteau: 'What does being a 'better home for PLWHA mean?' A shelter, involvement in day to day activities, or the facilitation of access to care and treatment?'**

Over a short period of time, a workplace programme for meeting RDN staff needs in regard to prevention, care and treatment was developed and implemented. Staff are educated and informed about various aspects of HIV/AIDS at regular training sessions (about two hours every month) during the working day. In addition, information on all aspects of HIV/AIDS is displayed on a bill board at the cafeteria – headlined LEARN MORE ABOUT HIV/AIDS – and there is a readily accessible file containing information on access to care and treatment services. There is a continuous evaluation of the training and an assessment of training needs. Male and female condoms are available in all RDN toilet facilities free of charge.

Within the RDN, there is a general belief that the programme, and Dorothy's involvement, has created an environment which is more conducive for staff and volunteers who may be HIV positive or living with AIDS. Staff are more comfortable discussing issues of HIV/AIDS. They feel able to ask for counselling and testing, and to talk to Dorothy over a morning coffee or tea

about their fears and concerns. She is the focal resource person on HIV/AIDS for staff, a job Couteau believes would have been impossible for him, as an expatriate and a member of senior management, to have done.

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***‘You cannot claim you are a home for “those living with”, and you will not take your work further if you don’t have the involvement of a person living with HIV/AIDS.’***

Dorothy Odhiambo.

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However, Dorothy’s appointment and the establishment of a workplace programme on HIV/AIDS confronted the Head of Delegation Francoise Le Goff and her HR Manager Winnie Maganda with a major challenge: the provision of free or low cost anti-retroviral therapy. Not only had Dorothy received this in her previous job but Couteau and Le Goff agreed that access to ARVs is an essential part of any workplace programme.

‘If the Federation is to offer ‘a good home’ for people living with HIV/AIDS, it must provide access to effective care and treatment,’ stressed Couteau. This is a particularly key issue in African countries where only a small proportion of people needing ARV treatment have access to it, as neither individuals nor the national health services can afford to pay for this therapy. ‘If we don’t ensure access to treatment’, said Couteau, ‘why are we empowering people such as Dorothy Odhiambo? For them to go to the grave?’

A major achievement in Nairobi was that the RDN, through its Human Resources Manager, was able to renegotiate its health insurance package ; it now includes 100% free access to ARVs for all staff (and their families) who are HIV positive. It was a hard and complicated deal, and it may not be possible to replicate it in other countries.

Everyone consulted for this report – especially people who are living with HIV/AIDS - agreed that access to ARVs could prove a major obstacle to the development of the partnership between the Federation and the associations and networks of PLWHA. ‘Otherwise’, said Couteau, ‘we’re building capacity that will soon disappear without effective treatment.’

### **Access to antiretroviral therapy**

In the short time period of this report being researched, the Federation has started a process to provide ARV therapy to staff and volunteers. This is an example of the Federation’s capacity for flexibility, pragmatism and living up to its humanitarian Principles – and the determination of the HIV/AIDS team in Geneva and the field. Bermejo said it is a direct result of the partnership. At the May 2003 meeting of the Federation’s Governing Board, it was agreed (see below) that a fund would be established to give access to ‘life-saving drugs’ including anti retroviral therapy to Federation staff and volunteers ‘regardless of their country of origin.’

Each National Society will be asked to contribute to the fund. A small number objected, because they saw it as encouraging people to volunteer for gain, thus directly counter to one of the fundamental Principles. The African members of the Board argued strongly that this was a matter of ‘organisational survival’ in many countries and that there should be solidarity with brothers and sisters in the Movement who are dying from AIDS every day.

**The Governing Board Resolution, May 2003**

**4.3 aware of the devastating impact of HIV and AIDS on families, entire communities and countries,**

**valuing the tremendous contribution Red Cross Red Crescent individuals living with HIV and AIDS often make to enhancing the AIDS response;**

**conscious of the unprecedented challenge HIV and AIDS poses in terms of organizational continuity, and even organizational survival, and well aware of the need of an extraordinary humanitarian response;**

**took note of the discussion of the HIV/AIDS governance group and the report of the chairman of the Health and Community Services Commission and, at their recommendation;**

**called for National Societies and the International Federation Secretariat to make every effort to pursue greater access to lifesaving drugs for all who need it;**

**requested the Secretary General to establish a fund that provides for access to lifesaving drugs (including anti-retroviral therapy) to Red Cross Red Crescent staff and volunteers, regardless of their country of origin;**

**requested all National Societies to raise a voluntary annual contribution for this fund and recommended using the equivalent of 1% of that society's statutory contribution (barême) as a minimum fundraising target;**

**took this extraordinary measure to ensure the survival of humanitarian workers, which is essential to maintain National Societies' capacity to deliver humanitarian assistance and can in no way constitute a precedent for other programmes;**

**in order to make it operational as soon as possible, requested the Secretary General to present, by the next session of the Board, statutes, guidelines and clear operating mechanisms for the Fund and to do this in such a way that the Fund is also open for contributions from other sources;**

**decided to request the next General Assembly to endorse the request for contributions to the fund by National Societies;**

It is too early yet to see what the response from the National Societies will be and what emphasis needs to be given to other sources to finance the new fund.

The final element in the RDN's workplace programme was a training course for Federation Workplace Peer Educators, held in Nairobi in May 2003. It was the staff at the RDN who asked for peer educators to be trained. The course brought together 20 participants - staff from the Regional Delegation, Kenya Red Cross Society (which has implemented its own HIV/AIDS workplace programme) and Nestlé Kenya which is supporting the Kenya Red Cross work on HIV/AIDS.

Through the HIV/AIDS Workplace Programme, staff and volunteers within RDN increased their awareness of, and knowledge about, the epidemic – they improved what some call their 'AIDS competences.' But this was only part of ensuring the success of the partnership in East Africa. Couteau and his team within the Regional Delegation, together with NAP+, had to build up the skills and resources of associations of PLWHA, and of National Societies. They also used every possible opportunity to advocate for the partnership at global, regional, national and community levels.

## Building skills

One reason for partnering with PLWHA is to show the human face of the epidemic, so promoting understanding and combating stigma. PLWHA organizations have long recognised the power of this, and NAP+ has for some years had a programme that specifically uses the human face perspective. This is the Ambassadors of Hope programme, and the RDN – that is, Couteau and Odhiambo, one of the earliest Ambassadors – recognised the value of this in promoting the partnership and building up much needed skills among PLWHA. A workshop was organized as part of the joint training initiative between RDN and NAP+.

It was held in Pretoria in September 2002, with a number of Ambassadors of Hope and five National Societies (Eritrea, Ethiopia, Kenya, Tanzania, Uganda). Participants came from Botswana, Eritrea, Ethiopia, Kenya, Lesotho, Malawi, Mauritius, Namibia, Rwanda, South Africa, Swaziland, Tanzania, Uganda, Zambia and Zimbabwe. Funding and technical assistance were provided by UNAIDS, the Federation and the Cape Town - based Policy Project.

Staff and volunteers from the Federation who are living with HIV/AIDS joined members of NAP+ and were trained as Ambassadors. The aim of the workshop was to train potential ambassadors for future missions; existing ambassadors shared their experiences and lessons learnt from previous missions, and participants received training in policy formulation and advocacy, public speaking and other communications skills, and media relations. The work is also intended to enhance the greater involvement of PLWHA in Federation activities, to promote networking and the GIPA principle, and to prepare them to be major actors in the Federation's campaign against stigma and discrimination.

During the workshop, strategies were developed for joint Ambassador of Hope missions to use in order to strengthen advocacy and networking for stigma reduction. Ambassadors visit countries to support PLWHA, helping them where necessary to form support groups and to promote care and treatment, and to sensitise and lobby governments, National AIDS Commissions/Councils and other influential groups to respond effectively to the epidemic. Michael Angaga, NAP+ Regional Coordinator, noted that some National Societies helped NAP+ to reach groups of PLWHA unknown to NAP+, for the workshop, as the societies were already working with them.

Following the workshop, Ambassadors of Hope will go on mission to work with National Societies and to develop partnerships between them and associations of PLWHA.

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***'Ambassadors were urged to utilize the comparative advantage of the Red Cross/Red Crescent Movement, namely the presence of volunteers and networks at grassroots/local community levels. These networks and human resources represent a potential for local /ambassadors – gallant positive persons willing to break the silence at local community level. Utilizing this untapped human resource would allow PLWHA in the Red Cross Red Crescent Movement to transcend their presence as 'tokens' and become effective actors and advocates, involved in policy formulation and implementation at regional, national and local levels.'***

Report by David Mukasa,  
a volunteer with the Uganda Red Cross Society who attended the workshop

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## Ambassadors of hope

The Ambassadors of Hope programme was initiated by NAP+ in 1995, and supported by the UNDP Regional project on HIV and Development, Dakar. Previously NAP+ members had been on fact-finding missions to countries and they believed that there was a need to present the problem of HIV/AIDS as a 'living reality' in the form of ordinary men and women from every social sphere of African society. A second principle behind the programme is that every PLWHA has 'an intrinsically valuable, unique experience and understanding of the epidemic which everyone on the continent needs to know about. The third principle is that the process of actively and unreservedly sharing of oneself and one's most intimate, often painful experiences, would serve as very powerful therapy for the Ambassadors and their audiences – 'therapy that hopefully would lead to personal action in peoples' lives and ensure that the focus of HIV/AIDS activity remains squarely on the humanity behind the statistics.'

There is a danger that such 'therapy' can turn into the undisciplined venting of feelings and experiences, that is neither productive nor useful in meetings of professional bodies. Critics of the Ambassadors of Hope programme would urge ambassadors to avoid this. Only then can the ambassadors more effectively use meetings for their full potential.

The Ambassadors of Hope programme, though still small scale, has begun to address the fact that so many PLWHA, because of stigma and discrimination and other issues around their condition, lack the skills needed to participate in policy making and programme implementation. This has been a major issue for GIPA and now for the partnership between the Federation and GNP+ and its networks.

The first NAP+ Ambassador of Hope missions were in 1996, with four missions to Chad, Gabon, Guinea Conakry and Mali. An Ambassador of Hope (there are currently 32 Ambassadors representing 15 African countries) is an envoy of the African network of people living with HIV/AIDS (NAP+) 'whose expressed mission is to demonstrate the true human cost to Africa of HIV/AIDS, including the cost of inaction by governments.' (Toolkit) 'The Ambassador's role in country complements that of government and communities in galvanising society to respond en masse to the very personal, the social and economic devastation of HIV/AIDS and to bring hope to the millions of people infected and affected by HIV/AIDS.' Finally and perhaps most importantly, they serve as positive and empowering role models for PLWHA; 'currently living in fear and hopelessness,' showing them that being diagnosed HIV positive is not the 'end of the road' and that people continue to enjoy a good life. It is thus a strong tool against discrimination and stigma.

The programme has several aims: one is to increase the visibility of PLWHA at country level, thus ensuring that their voices and concerns are heard by governments and at other appropriate levels. By doing this, and providing positive role models, the programme aims to improve access to care and treatment, and to promote behaviour change.

Ambassadors are carefully chosen and trained before going on missions. As outsiders to the countries they visit, they can talk more freely and, it is hoped, can influence governments. They cannot be thrown into jail as subversives, stressed Angaga. They hold public meetings, appear on TV and radio, as part of a general awareness raising sensitisation, and they work with local associations of widely as to train and build capacity. They are also expected to be involved in work on HIV/AIDS in their own countries.

### Capacity building and advocacy

At a global level, the International AIDS conference in Barcelona, July 2002, was the perfect opportunity for advocacy, as described earlier. There Patrick Couteau and Dorothy Odhiambo presented their plan of action for the partnership, with some considerable success. The Uganda Red Cross Society agreed to support the International Conference for PLWHA in Kampala October 2003, and the Norwegian Red Cross donated (60,000 CHF) exclusively for the RDN's work on the partnership. (*see above for more detail on Barcelona*)

Advocacy at a regional level took place at the annual NAP+ Delegates conference, held in Pretoria in November 2002. The RDN provided logistical support and seconded a French-speaking volunteer to NAP+ to communicate with associations from Francophone countries. As well as a number of National Societies from the region, representatives from two other Federation regions – Southern Africa, and West and Central Africa – attended and took back strong 'messages' about the partnership to their HQs. The RDN held a satellite meeting for all associations of PLWHA, to discuss the partnership between NAP+ and RDN and to explore the potential for this in their countries. There was general (unanimous?) agreement at the conference that the partnership should be extended throughout the whole of the African continent. (*see above for partnership activities in other African regions*)

Unfortunately NAP+ is in a critical situation in terms of capacity. Donors have not fulfilled their financial commitments and it is not well supported by members. Odhiambo and Couteau have helped to raise funds but it is a constant challenge for NAP+ to sustain itself.

On World Red Cross Day (8 May) 2003, the RDN launched a poster competition on the subject of stigma and discrimination, for staff, volunteers and associations of PLWHA. Couteau explained that this is a simple way to provoke dialogue between them all. The posters will be displayed at the International Conference for PLWHA in Kampala, October 2003, and the winner will be offered a scholarship to attend the conference.

### Work with National Societies.

One of the great advantages the Federation offers GNP+ is its involvement with, and closeness to, communities at grass roots level. In contrast, associations and networks of PLWHA tend to develop in major cities. They are too constrained by lack of human and other resources to reach out to smaller and rural communities. But only when these communities are reached and empowered can programmes of prevention, care and treatment be truly scaled up, and the battle against stigma and discrimination be fully engaged. Couteau says that his dream is that through the partnership all communities will be reached, thus 'decentralising the empowerment of PLWHA.'

At national level, Couteau and Odhiambo are working to develop in tandem the capacity of National Societies and associations of PLWHA. By July 2002 the majority of National Societies had developed five year strategic plans and had started implementing them. A few were already working with groups or networks of PLWHA, mainly in home-based care activities, and all agreed with the concepts of partnership and workplace programmes on HIV/AIDS.

As the work continues on the partnership in East Africa, there is considerable frustration – within and outside the RDN – with its progress, especially at grassroots levels. They have not yet reached out to small communities. There are not enough people to increase the momentum, and there are concerns too about its development. As Couteau explained, they are 'learning by doing' but at the same time they must be visionary, to anticipate future challenges and needs and steer the

partnership in the right direction. He and others, notably Françoise Le Goff, head of the RDN, criticised the Federation secretariat for not foreseeing some of the practical difficulties, such as health insurance for HIV+ employees. Le Goff: 'When the agreement was made in Geneva, no one asked me how I would do this. We've learned in an expensive and painful way. The team in Geneva is good, ready to do anything we need. But they don't know what we need.'

This is the nature of such an innovative approach, and perhaps inevitable given the tragic scale of the epidemic and the urgency to act. Time is a luxury; much thought has gone into the partnership at all levels, but doing and planning had to go hand in hand. The success so far in East Africa – and the enthusiasm and warmth with which the concept of partnership has been received – is therefore even more impressive.

### National Societies in partnership with PLWHA networks

By May 2003, several of the National Societies in the East African region had made considerable headway in developing a partnership with associations of PLWHA.

**Djibouti** is providing very practical support by 'hosting' the new national organisation of PLWHA called 'Oui à la vie', in its own offices. The physical closeness is helping the partnership to grow, and gives it a higher profile in the country. As so many networks of PLWHA lack resources, this may be a good example for other National Societies to follow.

**Eritrea** has embarked upon a campaign against stigma and discrimination in partnership with the relatively new national association of PLWHA, Dawn of Hope. In order to build up its skills, the RDN sponsored representatives from the association to be trained as Ambassadors of Hope at the workshop in September 2002, and to attend the NAP+ conference in the following November. The association has now nominated one of its members to be the focal point for the partnership and the National Society proposed that she become their new HIV/AIDS coordinator. She refused for personal reasons.

**Ethiopia** has signed a formal Memorandum of Understanding with Mekdim, one of the country's two associations of PLWHA. Mekdim will identify clients that could benefit from the National Society's home-based care programmes; participate in the training of care givers, and train and support volunteers to provide nursing and psychosocial support to PLWHA.

**Kenya** has involved volunteers from the PLWHA association in Nairobi. One of them recently addressed a governance meeting where the HIV/AIDS policy for staff and volunteers was being discussed, and she encouraged them to set up a strong workplace programme. In several branches where home based care programmes exist, the National Society has helped PLWHA to come together in support groups and empowered them to become part and parcel of the prevention and care programmes. In Mombasa, for example, the partnership with PLWHA existed before the more formalised partnership was established.

**Madagascar** National Society, with UNAIDS, is supporting an emerging and nervous association of PLWHA. Because of its initial reluctance to go public, the National Society is offering the group a room in their offices to meet in total security.

**Rwanda** National Society has supported the setting up of 18 associations of PLWHA at community level, and is working with them on home based care programmes. The

PLWHA are trained by Red Cross volunteers, some of whom are themselves HIV positive and open about this. 'They are actors and clients within the programme.'<sup>5</sup> Within the community it has created an atmosphere of openness, and the Red Cross/Red Crescent is perceived as a welcoming organisation attractive to PLWHA. There is a clear 'change in mindset' from seeing PLWHA as victims and beneficiaries to being 'frontline actors' in HIV/AIDS, prevention, care and support.

**Sudanese** National Society has requested that Dorothy Odhiambo supports them in empowering the Sudanese associations of PLWHA.

### Uganda case study

The Uganda Red Cross Society has been at the forefront of work on partnering with PLWHA in East Africa. It is promoting the partnership actively at national and branch level, and also in partnership with other NGOs and the government's National AIDS Commission. This is partly because of its past work and also because of the involvement of a very committed and talented volunteer David Mukasa who as a board member of NGEN + – the National Guidance and Empowerment Network of People Living with HIV/AIDS in Uganda, is their link person with the URC.

NGEN+ was set up in 1996 to bring together PLWHA to take part in advocacy, prevention and care projects, and to support and empower them. There are networks of PLWHA in 22 out of 56 districts in Uganda, and mobilising PLWHA involves training them in positive living, communications skills, networking, lobbying and advocacy, information on prevention and management of the disease.

David, a teacher when was diagnosed HIV positive in 1989, volunteered to work with the Uganda Red Cross Society when there was a cholera outbreak in Kampala in 1997. At that time he had been working in HIV/AIDS activities, in post test clubs, the AIDS Information Centre and suchlike, and was an Ambassador of Hope, giving testimonies in schools and fighting stigma and discrimination. Since then, he has been a full-time volunteer at the Red Cross, spearheading much of their work on HIV/AIDS and promoting the GIPA principle.

He is keen to involve more PLWHA in this work, recognising how much they have to offer. He is to some extent involved in the Red Cross's strategic thinking and planning, and has drafted some important documents for the society and the partnership. Mukasa is very positive about the partnership, having seen its development over three years. But he warns the Federation: 'PLWHA expect a lot from you'.

The Uganda Red Cross Society has worked with PLWHA since the early days of the epidemic. It was the country's civil society, including the National Society, that pioneered HIV/AIDS activities in Uganda and then – successfully- put pressure on the government to do more. Uganda, almost alone in Africa, has managed to slow, if not halt, a major outbreak of HIV infection over several years.

In the 1990s, HIV/AIDS was the National Society's largest programme, and it was the first humanitarian organisation to establish support programmes for PLWHA, such as treatment and feeding centres. It also set up home-based care programmes within its branches. From the mid 1990s, it reverted to more traditional Federation activities. But since the partnership with GNP+ was launched, its work on the epidemic, and its involvement with PLWHA, has been growing, at national and branch level.

So how is the partnership developing within the Uganda Red Cross Society? It is trying to make itself a more 'comfortable home' for PLWHA and Mukasa and other PLWHA are closely involved with plans to establish an HIV/AIDS workplace programme at the Kampala HQ and in the branches. By March 2003, awareness raising and education sessions had taken place in Kampala, involving PLWHA. A workplace programme that will promote and provide access to counselling and testing was in the pipeline, and staff were encouraged to speak confidentially to Mukasa if they wished. But at that point it was still clear that staff who were HIV positive were not comfortable with disclosure because they were afraid of being stigmatised. This clearly made it difficult for the partnership to be more visible. Senior management also said they were 'a bit threatened' by the issue of antiretroviral therapy as the society's health insurance scheme will not currently pay for 100% provision.

At the national level, the National Society has actively promoted the partnership, through the anti-stigma campaign. It is also part of the local organising committee of the International Conference for PLWHA and has provided office space and equipment for the conference secretariat. Two local staff members have volunteered to man the secretariat. URCS is willing to mobilize volunteers to support logistics during the conference and to provide services such as First Aid. It also supported the Local Organising Committee in resource mobilization for the conference.

The Uganda Red Cross Society has PLWHA working successfully as volunteers in home-based care programmes, counselling, blood donor programmes and Positive Living clubs. PLWHA who are benefiting from URCS activities, such as home-based care, are encouraged to become volunteers and care facilitators, and participate more fully in planning and suchlike. They are encouraged to share their experiences and be open about their status because, as one project officer explained to a group, this helps to combat depression and AIDS complications.

URCS is working with the National AIDS Commission and NGEN+ at district and provincial levels to mobilise communities to mitigate the impact of the epidemic through orphan care and support projects, advocacy for stigma reduction and distributing relief supplies in the war-torn northern regions.

It is working closely with NGEN+ on the anti-stigma and discrimination campaign, as well as with other NGOs – NACWOLA (National Association of Women Living with HIV/AIDS), AIC and TASO. These organisations had also participated in the RDN initiatives such as the training workshop for Ambassadors of Hope. Representatives from these organisations strongly believe in the partnership but some expressed the view that in Uganda, it needed more commitment and direction to be more effective.

Jane Mwirumibi, Project manager of NGEN+, stressed how well the partnership was working, and that the Red Cross does not just 'trot out PLWHA at big events and conferences, they really are involved.' She said that they were always consulted by the URCS on HIV/AIDS activities, and that their ideas were always taken on board. Through its community network, the URCS is helping Mwirumibi in her role as Secretary of the local organising committee for the International Conference for PLWHA, to reach PLWHA in the districts that NGEN+ do not know. She and her colleagues recognise the ability of the Red Cross Red Crescent to mobilize people.

In villages and trading centres, where Red Cross volunteers run home based care projects, their work is appreciated but the major concern of people living with HIV/AIDS was access to ARVs, as well as drugs for opportunistic diseases, and care for orphans. However much they appreciated what the URCS was doing for them, these were their priorities. In one project a few miles outside Kampala, young women, many with small

children, welcomed the planned initiative by the Red Cross staff and volunteers to set up income-generating activities.

**'Maybe we haven't said enough about it but we are moved by the generosity and openness of URC, we haven't seen it in any other organization. We should give it lots of encouragement. No, we're not worried about being taken over. This partnership started long before the 2001 agreement but that formalised it at a higher level.'** Jane Mwirumibi, NGEN+

## Southern Africa

### region of Red Cross Red Crescent: a snapshot

As the 'champions' for the partnership in Africa, Couteau, Odhiambo and their colleagues have encouraged and supported other regions to follow suit.

In March 2003, the Regional Delegation of the Southern Africa Red Cross and Red Crescent (RDH) convened a workshop for all the Southern African National Societies to discuss progress on HIV/AIDS activities and plan further strategies. This included a partnership with networks of PLWHA.

The 10 countries in the Federation's Southern Africa Region have some of the highest rates of HIV/AIDS in the world, with four of them having adult prevalence rates of more than 30% : Botswana (38.8%), Lesotho (31%), Swaziland (33.4%) and Zimbabwe (33.7%). Many of these countries have a deteriorating economic situation and food insecurity, exacerbated by the epidemic's impact.

A psychologist in South Africa reported that she had never seen as many Federation volunteers so stressed as they were working with HIV/AIDS and its impact.

The epidemic has been the main priority of the regional Delegation since 2000. In 2001 Bongai Mundeta, the Regional HIV/AIDS Coordinator, hired consultants to carry out baseline surveys in the region's 10 countries and then five year plans were drawn up. Each country has also appointed a HIV/AIDS Coordinator.

Regional strategy focuses on home-based care, following the successful precedent of projects in Zimbabwe, plus prevention, advocacy, mainly with PLWHA, and orphans. Zimbabwe Red Cross has run home-based care programmes since 1989, and South Africa since 1994. The detailed strategy documents produced by the RDH consistently refer to the importance and relevance of involving PLWHA, promoting support groups and working with networks of PLWHA on home-based care, advocacy, combating stigma and suchlike. But as in other regions, there is considerable variation in levels of activity on HIV/AIDS among the countries, as well as to partnership with networks of PLWHA.

In some countries an informal partnership already existed. But in others, PLWHA have been viewed solely as the beneficiaries of services. There is as yet little understanding of the concept of GIPA. Several National Society staff were unaware of the existence of networks of PLWHA even when at district level Federation volunteers may be working with PLWHA.

For Bongai Mundeta, working with PLWHA is not a new concept. When Mundeta was Secretary General of the Zimbabwe Red Cross, she was approached by a woman living with HIV/AIDS from the Zimbabwe network, who questioned the ability of the National Society to work on HIV/AIDS without involving PLWHA. After some discussion, Mundeta recognized the importance of partnership. She identified PLWHA in every

province of Zimbabwe and linked them with the Zimbabwe Network of PLWHA. Since then a team from the Zimbabwe network of PLWHA has always been involved in the planning of all HIV/AIDS activities. In her role as HIV/AIDS Coordinator for the RDH, Mundeta has asked all the National Societies to identify groups of PLWHA and to involve them in their work on HIV/AIDS.

For some years, Mozambique National Society has involved PLWHA in training their volunteers. More recently, other National Societies such as Botswana have brought PLWHA to training workshops. In the South Africa Red Cross at branch level, support groups have been established among clients of home-based care projects, and clients have been referred to the network of PLWHA. Also in South Africa, the National Society has trained a member of the Network of PLWHA to be a home-based care facilitator.

Mundeta has also started to work with Ambassadors of Hope, especially for the anti-stigma campaign. Regionally, very few National Societies have pursued advocacy against stigma and discrimination. Mundeta is encouraging them to work with Ambassadors of Hope, and to involve them in planning support groups, which are so important at village level for PLWHA, and work with orphans.

At the Harare workshop in February 2003, Ambassadors of Hope (from almost all Southern African countries from the region) took part; they gave presentations, and worked with NS staff in group sessions to work towards facilitating the partnership with PLWHA. This followed on from the NAP+ meeting in Pretoria in December 2002, where RDH had promised that an action plan with the Ambassadors would be initiated.

According to Mundeta, the formal partnership between the Federation and GNP+ has undoubtedly provided an impetus to National Societies' work in her region. The Secretary-General of every Southern African National Society has now agreed to work with networks of PLWHA.

This can mean help at a very practical level. Most PLWHA organizations do not have an office. In Namibia, the National Society has provided office space to Namibia's network of PLWHA – 'Lironga Epani', 'Learn to survive.' The network is chaired by Emma Tuaepea who had been a youth volunteer with the Namibia Red Cross youth, and is now a lively and effective Ambassador of Hope, and Vice President of NAP+. The partnership – that is, the sharing of the office – was launched at a public event, and a contract was signed. The Secretary General of the Namibia NS has said that the partnership has improved the 'image' of the Red Cross Red Crescent there, although there have been some disagreements, now resolved. This support from the Red Cross has helped the network to develop and it now operates in all 13 regions of the country, offering counseling and other forms of support. The Namibia Red Cross also pays travel costs for Emma and her colleague – for example, to carry out prevention programmes – and helps in many other ways. In one district, the Red Cross provided space for a support group. The Red Cross encourages PLWHA to become volunteers and invited Emma to a donors' meeting so that the network might receive some extra funding. At Christmas 2002, Red Cross volunteers took food to 30 – 40 members of the support groups who were very sick.

Emma Tuaepea explained that 'it works very well because they have mutual respect. Both are professional organizations, and through the Red Cross I can reach leadership of the country, the government. I mainly deal with SG and Deputy of the RC, and we also have a strong relationship with UNAIDS.'

She added: 'It is very important to know what you want, and to ensure that you're keeping to your mission, your vision. No other organization can come in and drive ours but we're very open to partnership and support. This is an opportunity and challenge for both organizations. Together we can make it.'

## Honduras case study:

### the partnership between Honduras Red Cross Society and the Asociación Nacional de Personas Viviendo con el VIH-SIDA en Honduras (ASONAPVSI DAH)

#### The HIV/AIDS epidemic in Honduras

There are 1.5 million people living with HIV/AIDS in Latin America. Within the region, 12 countries, including Honduras, have an estimated prevalence of 1% or more among pregnant women. The epidemics are well established in the region and without a strengthened response, they could spread more quickly and more widely.

More than half of all reported cases of people living with HIV/AIDS in the Central American region are in Honduras, and more than 13,000 children have been orphaned by AIDS. The official rate is 1.6 % but there are pockets of higher infection rates among specific populations such as men who have sex with men and injecting drug users. A recent study in two Honduran cities revealed an HIV prevalence rate of 13%, very low rates of condom use, high numbers of sexual partners and low perceptions of risk. A new group being surveyed is prisoners. A study in three urban prisons in Honduras has shown an HIV prevalence rate of almost 7% among male prisoners in general, and almost 5% among those aged 16-20. Infection rates are also rising in rural areas where people struggle to make a precarious living, and among women.

Factors helping drive the spread in Honduras and other countries in the region include a combination of huge inequalities in income and quality of life, and high population mobility. Central America's worsening epidemic is concentrated mainly among socially marginalized sections of society. Economic difficulties in Honduras and other countries in the region will, unless reformed, make it even more likely that the epidemic will spread and increase in its impact.

In the country generally, there has not been a response on the scale needed, and levels of awareness are low among the general public. There are several reasons for this; an inadequate response from the government to HIV/AIDS, and the fact that many PLWHA are socially marginalized. Rates of HIV/AIDS are higher among men who have sex with men, sex workers and injecting drug users. PLWHA therefore have to contend with huge stigma and discrimination, and are usually wary of disclosing their status or seeking help. Testing and counseling are not widely available, and cultural taboos in a very traditionally conservative society constrain plans for prevention and distribution of condoms. People who become sick with AIDS-related conditions have to rely on a few public and private hospitals, and people with HIV/AIDS have met with stigma in these places and been turned away. There is no home-based care in Honduras for people living with HIV/AIDS. Much of the help available – for example, support groups – is provided by the branches of ASONAPVSI DAH (the national network of people living with HIV/AIDS).

This situation is changing; HIV/AIDS is now a government priority, and some significant steps have been taken against the epidemic. A HIV/AIDS Special Law has been passed, the National AIDS Strategic Plan has been formulated and the government is working (from forum's report) on the approval of funds for antiretroviral medication emergency purchase. The Honduras National AIDS Forum, aimed at strengthening the national response and offering enhanced participation to groups infected and affected by the epidemics, was set up at the end of 2001. Its main objective is 'promoting and assuring an extended multi-sector participation, in order to support the

national response to HIV/AIDS, and strengthen the National AIDS Commission (CONASIDA).’ The Honduras Red Cross is a member of the Forum.

Honduras was chosen for this case study because of its high HIV prevalence in the region, and because the National Society has a dynamic relationship with the networks of PLWHA.

### **Work of Honduran Red Cross on HIV/AIDS**

The Honduras Red Cross has carried out activities on HIV/AIDS for several years – for example, in the late 90s there was a project of peer education with youth Red Cross volunteers in schools. Honduras was the first National Society in Latin America to carry out a survey on HIV/AIDS in the 1980s. But as in many National Societies, the work has been fairly ad hoc with no clear strategy or policy.

In line with Federation policy in 2002 the Honduras Red Cross began to increase its work on HIV/AIDS. The National Society already had links with associations of PLWHA before the formal launch of the IFRC/GNP+ partnership, but this has strengthened since July 2001. The President and senior management of the National Society have very publicly displayed their commitment. In May 2003, the Honduran Red Cross and the national network of PLWHA – ASONAPVSI DAH (Asociacion Nacional De Personas Viviendo Con El VIH-SIDA En Honduras) - were, after some heated debates, close to signing a formal agreement of partnership.

‘It is a shame and pity that not so many Red Cross Red Crescent Presidents take the situation of HIV/AIDS seriously enough. The epidemic is a huge problem and we need to reach more of our people. Too many have died. We have to fight the stigma. And access to ARVs must be a priority for Honduras.’ President of Honduras RC, Doña Meneca de Mencia.

But there is still a long hard road to travel and Federation people in the region are concerned at the fragility of the partnership. How sustainable is it given the very limited resources, especially personnel, available? As in other countries, the partnership has gained its momentum from a small number of deeply committed individuals from the Federation and the networks of PLWHA.

The Head of Delegation for the Federation was Giorgio Ferrari and, following his experiences of working for the Federation in Africa, he is wholly committed to working on HIV/AIDS. He clearly sees the potential of the partnership. But he only worked 50% as HOD (his other job is Head of the Regional Delegation for the Italian Red Cross) and HIV/AIDS was just one of many tasks confronting him daily. He left Honduras in July 2003 and it was not clear how his post would be filled. Given the scarce manpower there was considerable anxiety within the National Society at Ferrari’s departure.

One of Ferrari’s first projects with Honduran Red Cross was aimed at combating stigma and raising awareness – both in – house and the outside community. Stigma against people living with HIV/AIDS is a major challenge in Honduras. The President of the National Forum on HIV/AIDS, Xiomara Bu, said that there were two epidemics in Honduras - HIV/AIDS and the stigma against it. ‘In some ways, the second one is worse. It prevents people going for testing and other forms of support. It is a barrier to the collection of sound statistics on the epidemic, as well as to advocacy and education among the general public.’

The project included setting up a workplace programme on HIV/AIDS within Honduras RC, recognizing the need to raise awareness and inform staff and volunteers about HIV/AIDS, as well as work with some of the branches.

But for various reasons – personnel problems, delays and shortfall in funding, limited support - sufficient resources were not forthcoming and Ferrari achieved, he said, only about 20% of what he had dreamt of doing. He wanted to employ a person living with HIV/AIDS for the pilot project but there was no-one suitable at that time.

For some of the same reasons, the partnership between the network of PLWHA and the Red Cross has evolved in a rather more haphazard, less planned fashion than in other places. However committed, people do not have the time to devise strategic frameworks. They have considerable vision but policy making is done ‘on the hoof’ as they dash from one meeting to another.

The National Society seems very committed to the partnership but its management, at the time of the visit, was still struggling to formulate its policy on HIV/AIDS and to become more ‘AIDS competent.’

There is a strong relationship with the local network of people living with HIV/AIDS – ASONAPVSI DAH. The ‘link person’ between the two organisations is an eloquent and committed woman, Marlene Daysi Rivera, a pre school teacher, aged 41 who discovered she was HIV positive when her husband donated blood. He has since died, and she has three young sons to care for. In 2001, she joined the National Society as a volunteer. Her work includes awareness raising within the Red Cross itself, educating school children and Red Cross youth volunteers, and promoting the partnership. She is well respected within the National Society and has a good relationship with senior management. She is now well known on the international AIDS stage, as the President Doña Meneca de Mencia chose her as the representative from the National Society to attend the International AIDS Conference, with the Director-General. Her lively and powerful presentation was well received. The President explained that it was a very positive sign that an activist can be promoted by the Red Cross, and that young people are far more likely to listen to Rivera talking about changing behaviour than to the President or the Director-General. Following Barcelona, Rivera addressed the governing board of the International Federation, at the time it was agreeing the new policy on HIV/AIDS, in November 2002.

Rivera and her colleagues are regularly in and out of the National Society’s office, for meetings, advising, planning – and just ‘being at home’. Their lively and animated style of working is an interesting contrast to the more sober manner of the Red Cross people. They also have an urgency about their work; understandably they want immediate change and results. However hard the National Society staff work, they cannot meet this demand. But what is noticeable is the warmth between the two partners and the respect commanded by Rivera. As the President Doña Meneca was discussing access to ARVs one morning, she consulted with Rivera who had just returned from a meeting on compliance to ARVs in Guatemala, run by the regional network REDCAR (Marlene had recently become the focal point for REDCAR in Honduras). The President suggested to Marlene that the National Society sponsor someone from REDCAR to come to Tegucigalpa to talk to them about generic ARVs.

## Awareness raising and combating stigma

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*‘The problem is that people talk about the fact that “they” can infect us, not that we are killing them with our stigma and lack of care.’*

Honduran Red Cross staff member

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Although a formal workplace programme on HIV/AIDS has not yet been put in place in the HQ at Tegucigalpa, some work has been done there - and to some extent in 15 of the branches – to raise awareness and change behaviour. Staff in the HQ in Tegucigalpa testified to the success of this work in raising awareness, increasing knowledge and combating discriminatory behaviour, at the same time as calling for more, ‘in depth’ training. The almost daily presence of Rivera and her colleagues has clearly contributed to this change in attitudes.

### The video – Romper el silencio

An important step in awareness raising and tackling stigma was the making of a video containing moving and frank testimonials from people living with HIV/AIDS. The idea grew out of meetings between the PLWHA network and youth volunteers at the RC, who had already participated in training in peer education. Both were keen to move forward in partnership.

It was not easy to find people willing to speak openly on camera about living with HIV/AIDS, but the involvement of APSONAPVSI DAH helped and nine people finally agreed to be filmed. The regional Network REDLA also agreed to put their logo on the video, which was sponsored by DFID, CIDA and UNAIDS, and to help in its distribution.

In the video, nine people, including Rivera, speak honestly and touchingly of living with HIV/AIDS, the struggles, the stigma and discrimination they meet every day, their hopes and their fears. Its straightforward approach – no preaching or obvious educational stance – is new to the region, but has been well accepted. It was the first video about PLWHA in Latin America where people’s faces were left uncovered. It was also an important learning experience for the young Red Cross volunteers who worked on it. Not only did they learn more about living with HIV/AIDS but also about the inequalities in living conditions in their country. They were directly confronted with their own prejudices.

The video will be distributed nationwide and within the region, along with guidelines on how best to use it to promote working with PLWHA and combating stigma.

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**‘Through working on the video, the youth volunteers became very close to the people in the video, and learnt a lot. On stigma, you learn how just words can hurt people. We also realized the impact of the video and how through working with people living with HIV/AIDS you really can help to improve their lives.’**

**Christian and Stephanie, youth volunteers**

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### Public events

The network of PLWHA and Honduras Red Cross Society have worked closely together on planning and implement public events such as World Red Cross Day and World AIDS Day. In 2002, on World Red Cross Day (8 May) the President of the Red Cross and the mayor of Tegucigalpa (the capital of Honduras) gathered together with many PLWHA to launch the anti-stigma campaign. A canvas was signed with messages and hand-prints from the mayor and his family, government ministers and PLWHA and it toured all the Red Cross branches in the country to promote the messages of the campaign. The involvement of senior leaders and politicians was hugely important in a society where stigma is rife.

In 2003, the Honduras network of PLWHA asked the National Society to take the leadership for activities on May 30, the day of worldwide solidarity and vigil for people who have died from AIDS. The planning meeting for the vigil brought together representatives from the National Society, PLWHA, the government, and other sectors of civil society. After at least three hours of lively and somewhat unfocused debate around the large table in the Red Cross's meeting room, a clear plan was agreed and people designated to implement it. This included the public launch of the video 'Romper el silencio' throughout Honduras. The mayor of Tegucigalpa also agreed to a permanent mural being painted on a wall in a central square.

The activities on HIV/AIDS in the Red Cross branches are at very different levels. The Director-General Maria Elisa Alvarado explained that resources are needed to support branches and to involve them in all areas of HIV/AIDS work, including partnership with PLWHA. This is even more important in rural areas where prevalence rates are on the increase, and stigma against PLWHA is possibly greater than in cities.

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**'Working with the Red Cross has given me so much...That is my motivation – being able to say to people, " I'm HIV positive too, and I'm full of life. I'm still a person in my own right. Being HIV-positive does not mean you are going to die today, tomorrow or whenever. You can still carry on working and playing an important role...It's like being born again – a new way of thinking.'**

**Marlene Daysi Rivera**

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Christopher Black/International Federation

## The partnership in Honduras

It is not just the partnership that is at an early stage but also the National Society's development of a strategy for HIV/AIDS. There is also a serious lack of resources, notably full-time experienced people in the Federation, and the country itself has been less advanced than others in its response to the epidemic. All these factors cause enormous frustration among the partners, and hinder the development of the partnership from a few projects and great enthusiasm to a grander vision and more strategic plan.

Several Federation people expressed the view that it was not unusual within the Movement for activities to be started before the formulation of policy. There is considerable concern about the fragility of the partnership, Ferrari stressed the importance of building lasting, sustainable foundations. He and his colleagues also wanted more clarity and support from the Federation's HQ in Geneva.

There is no shortage of ideas, energy, eager PLWHA and Red Cross volunteers, but there is a huge capacity deficit. There is also a divergence between the National Society and PLWHA when it comes to meeting the needs and expectations of PLWHA. As has been explained, the majority is poor, and this is exacerbated by the stigma they meet. Several members of the network had been sacked when their status became known; others had been turned out of their homes or rejected by families. They need help in finding work, financial support, as well as access to treatment and care. They are clearly looking to the Federation for help in meeting these needs, perhaps not surprisingly but obviously unrealistically.

The lack of clarity around the aims and objectives of the partnership, or rather the lack of nitty-gritty detail, doesn't help meet this challenge. But the agreement that was being hammered out between the National Society and APSONPSIDAH has had to confront this dilemma and focus on detail. For example, the PLWHA had requested special procedures for access to blood products. For them, one of the problems is that they cannot provide a blood donor when they need blood, as is required in Honduras. Dr Elizabeth Vinelli, Director of the National Blood Programme at the Red Cross, is hoping to persuade the National Blood Council to bring in legislation to exempt PLWHA from having to provide blood donors while also raising community awareness to increase voluntary non-remunerated blood donor recruitment and boost blood donation as the norm. She has also been involved in establishing another partnership project that has grown from the challenges of the blood programme (see box below) Another unresolved issue is a demand from the PLWHA network for special transport procedures for ambulances for them.

### Other partnership projects

Obviously PLWHA want and need work, they cannot exist on volunteering and the majority are from poor backgrounds. The involvement of PLWHA is also essential if the GIPA principle is to be fulfilled in Honduras. The National Society certainly cannot meet this need on any major scale but through some new projects, a few PLWHA are being employed in HIV/AIDS relevant projects.

The first is a project offering counselling and rapid testing. The idea for this project comes from the Red Cross blood bank (the Honduras Red Cross society is in charge of nationwide blood donations), and fact that many potential blood donors are turned away because they may be high risk. 'As a humanitarian organization, we've been concerned about this,' explained Dr Elizabeth Vinelli, Director of the National Blood Programme at the Red Cross. They know we won't accept their blood because their behaviour may have put them at risk of infection but then we just send them away. This project will offer counseling and rapid testing for such rejected donors and others.' The project is a partnership between the Honduras Red Cross Society, the American Red Cross Society and Casa Alianza, an NGO that works mainly with marginalized groups such as street children. The project, which will employ two PLWHA from APSONPSIDAH as counsellors, will also develop self-help groups that people referred to the project may wish to join. Minimum 'conditions' for self-help groups will be established. The network of PLWHA will also receive help in strengthening its organizational capabilities.

The second is a project in the North of the country, on the Caribbean coastline. The aim is to work with networks of PLWHA in the north to combat stigma. It will employ two PLWHA.

Access to drugs, especially anti-retroviral therapy, is a major issue. Some of the PLWHA pointed out that other NGOs they work with, such as MSF, do provide ARVs as well as office space.

There is considerable commitment to the partnership from the National Society and the network of PLWHA. Both partners are aware of the challenges confronting them and seem determined to succeed. Those who know the country and its culture are surprised and delighted by the way the National Society has responded to the idea of the partnership. Until fairly recently, it was as conservative as the society it springs from. It has gone, explained Ferrari, from the organization which gives 'milk to kids' to having a strategic alliance with PLWHA.

The NS has 'suffered' from limited staffing to work on the partnership but a new HIV/AIDS Coordinator, with considerable community experience, started work in April 2003 and the Health Commission within the Red Cross was being revived, with as a priority, a strategy for HIV/AIDS to be designed and implemented as quickly as possible.

Rivera and her fellow members of the network of PLWHA have managed to cross the social divide that exists between them and so many of the Red Cross volunteers. They are encouraging other PLWHA to volunteer for the National Society, 'marketing' this to their self-help groups. In Honduras, unlike other countries, the PLWHA who have disclosed their status tend to be poor. They feel angry that they are then doubly stigmatized and that middle class and richer PLWHA keep quiet. PLWHA are involved regularly with the Red Cross and seem to find it a 'comfortable home', a safe environment. The President was adamant that Rivera would be involved in the formulation of the HIV/AIDS policy. 'We recognize the importance of alliances.' The President regularly uses the word 'dignity' when talking about the partnership and work on HIV/AIDS. She stresses the importance of giving dignity to people who are marginalized and stigmatized by society.

## The results

There are two questions to ask: is the partnership established and if so, at what levels and where? And is it effective – that is, more than tokenism – and if so, how and for whom? Is it a true partnership – that is, with involvement and participation of PLWHA in Red Cross Red Crescent policy-making and programmes?

### Is the partnership established?

At the global level, the partnership between GNP+ and the International Federation has been launched and promoted very publicly. This is a result of several public events that have ensured a high profile for the partnership, and of the uniqueness of a partnership that would always attract attention. There has also been a willingness on both sides to be open and transparent from the beginning.

Good use was made of valuable opportunities – UNGASS on HIV/AIDS and the International AIDS Conference in Barcelona. At both, leaders of the Federation (International Governance, the Secretariat and the National Societies) committed themselves to the partnership, associated with people living with HIV/AIDS and were prepared to admit their shortcomings and to learn from members of GNP+. The leadership of GNP+ was involved in the running of both events, and impressed Federation leaders with their skills and professionalism. Didier Cherpitel, then the Secretary General of the IFRC, said he was worried in the beginning that the Red Cross Red Crescent might be 'used' or 'abused' because of its emblem and reputation. But discussions with Stuart Flavell, International Coordinator of GNP+, reassured him, as did meetings with volunteers and Federation staff who are HIV positive.

Both organizations have worked together at other major events such as the International Conference on Harm Reduction in Chiang Mai (June 2003) where they ran a satellite event together.

The Federation's Secretariat – the HIV/AIDS team particularly but also staff from communications and other departments- has used many opportunities to promote the partnership to National Societies – through its regional delegations, at events, through the websites, publications etc. The partnership is referred to as key in a number of Federation policy documents on HIV/AIDS.

The partnership is less well established at country and grassroots level, which is not surprising given the (relative) lack of capacity on both sides. There is always the challenge of stigma and discrimination, that tend to be greater in rural areas – in Honduras, for example – though still a huge problem throughout most affected countries. It is thus a vicious circle; the partnership aims to erode stigma but suffers its consequences. The partnership is more developed where individuals within the Federation are most committed and skilled in the issues of HIV/AIDS, and, though not always, where the PLWHA networks affiliated to GNP+ are strongest.

But even where the partnership is progressing – in the RDN and Honduras as described in detail here – it is still in its infancy and needs constant support and nourishment. Alvaro Bermejo, though delighted with the way the partnership has developed, is nervous about its ‘fragility’. ‘I think it will take at least another two years to become sustainable. It very much depends now on a few people making a big difference.’ He stressed the need for the Federation to help to strengthen the GNP+ networks, like NAP+, for example. There is concern in Honduras that the partnership is still ‘delicate’.

In the few months between conception and delivery of this report, it was noticeable that news of the partnership was spreading. More National Societies and PLWHA networks were beginning to work together.

It is important to remember that the partnership is very new, and that, as Giorgio Ferrari expressed it, it is very much ‘a journey of exploration together.’



Dorothy Odhiambo and Patrick Couteau at work in Nairobi.

## Is the partnership working and is it effective?

### The GNP+ perspective

Without exception, all the members of GNP+ who were interviewed were positive that the partnership is worthwhile and is beginning to make a difference – though some did say it was moving at a slower pace than they had hoped. Dorothy Odhiambo who was initially sceptical though involved, now believes that it is a ‘brilliant idea’ and that the Federation is unique in its attitude to humanitarian issues.

It is clearly a good working relationship. There is mutual respect and admiration – and affection. More than one GNP+ member said that the commitment and drive from the Federation people was ‘heart-warming’. ‘I’m really proud of them, they have courage,’ said Flavell. ‘They’ve really taken on board stigma and discrimination. And accepted the criticisms of their past work’. The Federation has made itself relevant to us and HIV/AIDS, it has ‘worked like hell’ to make its actions match its words.’

Hows pointed to similarities between the two organizations. ‘We are both a movement of people on a mission, They’re very principled. This strikes a chord with our activist mission. The majority of the work in both is done by volunteers.’

It does seem to be more, much more, than tokenism. Meetings where Federation leaders mix with PLWHA publicly are symbolic and significant, a public statement of intent and an effective way of combating stigma, raising awareness and suchlike. GNP+ members are involved in strategy and policy-making with the Federation, and evaluation of their activities – though by no means on a large scale. Such participation – the essence of GIPA - is essential for it to be a real and effective partnership. As Bernard Gardiner said, the involvement of PLWHA must be strategic, it has to be far more than testimonials.

### ***What has GNP+ gained?***

The capacity of the organization, including the national networks, has increased; the leaders have honed their advocacy skills and expertise, individual PLWHA have developed skills (for example, at the training workshop for Ambassadors of Hope in Pretoria), and on a practical level, some networks have been given office space and other practical support.

- Increased skills and expertise have led to increased self-confidence and self-esteem.
- A number of individual PLWHA have successfully competed for jobs as the partnership helped create a climate where they felt able and willing to work for the Federation.
- The technical expertise of members has been recognized and extended in outreach to the evaluation of Red Cross Red Crescent activities, involvement in workshops, conferences and training courses. GNP+ has also provided an annual critical review session on progress with the Federation Executive.
- Greater outreach to PLWHA in rural areas and more isolated or hard to reach countries such as Eritrea, Somalia and Sudan, Belarus, China and Jordan where networks are developing. The National Societies have more contacts with small communities, the grassroots, and are therefore better placed to reach PLWHA in those places.
- Maybe more slowly, but GNP+ is gaining improved access to governments and donors, the decision-makers and the funders. Flavell: ‘We’re more strategically positioned – for example, vis a vis the Global Fund, and the World Economic Forum has requested a GNP+ presence at meetings. We’re now related to as relevant.’
- Services being provided are being modelled and delivered in a less ‘paternalistic’ way – especially in the areas of primary prevention and outreach to youth.
- Greater outreach to more marginalised groups. For example, the Federation is putting more resources into harm reduction programmes for injecting drug users.

And the bottom line? ‘At the end of the day it’s all about creating a supportive environment for PLWHA,’ said Flavell. The Federation’s offices visited for this case study do genuinely seem to offer a comfortable – and stimulating - home for PLWHA, and scope to flourish and become more skilled. If this were to percolate through to every National Society and branch, the world really would be a much better place for PLWHA. Where it is happening, they receive respect and equality, basic human rights. As Javier Hourcade explained, it is about a 360 degree turn in viewpoint or attitude, from victims to peers.

### **The Federation perspective**

Without exception, the Federation staff and volunteers involved in the partnership are positive and enthusiastic. Without the partnership, they say, far less would have been achieved in terms of its work on HIV/AIDS.

‘The partnership has created a climate for us to engage wholeheartedly with the issues,’ explained Denis McClean, Head, Media Service at the Federation. ‘When you partner with an organization as particular as GNP+, it is a constant challenge to step up our game. It challenged us in communications to put a human face on the epidemic. It is too easy to get bogged down in sta-

tistics, facts. Our website news pages now contain far more human stories about the epidemic.' Indeed the Federation's website contains plenty of excellent, very readable material on HIV/AIDS, and video news releases are regularly produced and used worldwide on the human issues of HIV/AIDS – for example, on International Women's Day and for the UN World Assembly on Aging in 2002.

So has the Federation been the greater beneficiary? Alvaro Bermejo, Head of Health, believes so: 'I knew the partnership had potential to transform the Federation but the impact has been much greater than I expected. It has been a very powerful tool for change, has helped to change policy. There has been a change in the policy base; considerable evidence of the effects of disclosure and anti-stigma efforts. The recently passed Governing Board resolution on the ARVs fund is a good example of this.'

'I think we could have contributed more to GNP+ than we have. It may be that we still don't have access to PLWHA in enough places so need to spend time in building those relationships.'

Dr Elizabeth Vinelli, from the Honduran Red Cross agreed: 'The Federation benefits the most from the partnership because we are the ones who know the least.'

But Stu Flavell said that GNP+ always knew that their role was to help Red Cross Red Crescent sort itself out vis a vis HIV/AIDS.

The partnership has certainly worked as a tool for change. There has been a significant sea-change in the way the Federation is working on HIV/AIDS. They are now seen as a major and credible player in that arena, and have committed time, energy and resources to HIV/AIDS activities. The programme has scaled up from US\$3 million a year in 1999 to over US\$30 million in 2002. Sound policies and strategic plans exist and are in the process of being implemented. Bermejo stresses the importance of PLWHA's expertise and experience in helping the Federation achieve this. They have given 'added value'. 'The partnership has helped create conditions for PLWHA to be part of the organization.'

Thus the partnership has helped the Federation meet its mandate and its mission.

The anti-stigma campaign, though criticized by some, will have a major effect if it succeeds in harnessing the power of millions of volunteers worldwide. It has helped to promote the partnership and the 'human face' of the epidemic, thus making the Federation a 'better home' for PLWHA.

McClellan believes that the partnership has helped the Federation be braver and bolder in its public statements, such as press releases, on the epidemic. It has been honest enough to admit publicly its past inadequacies in HIV/AIDS work. It was brave enough to make a strong statement on access to drugs at the time of the WTO summit in Qatar in 2001. The then President of the International Federation Dr Astrid Heiberg called on its members to remind governments participating in the summit that "humanitarian concerns should prevail over commercial concerns". McClellan explained 'This was a major issue of public controversy and there were certainly some raised eyebrows within the Federation when the press release came out.'

More recently, in September 2003, the Secretary - General of the India Red Cross Society, Dr Vimala Ramalingam, addressed the UN Economic and Social Commission for Asia and

the Pacific. She called on governments and world leaders to commit to policies, however unpopular, that will make a ‘meaningful difference’ on the epidemic. She spoke of the dire consequences of stigma and discrimination, and the need to get rid of out-of-date attitudes and ignorance. ‘A practical example of what we must face is learning how to talk about sexual transmission of HIV. Despite what is sometimes said, it is possible to do this in all cultures, indeed it is the mark of a living and dynamic culture that it can adapt to ensure survival.’

There is pressure on the Federation as the biggest humanitarian organization in the world, having been so public in its policies, to ‘walk the talk’, to be true to its values and Principles and ethics. In the field of HIV/AIDS, many staff and volunteers are succeeding in doing this.

### UNAIDS perspective

“The partnership between the Federation and GNP+ might prove to be the best way to prepare organizations for the future in the worst pandemic mankind has experienced. HIV will, beyond doubt, change the world, especially high incidence countries. Coherent collaboration on certain key issues in relation to HIV will prepare individuals and organizations, and thus communities, to better tackle the effects of this global disaster, in which we happen to be in only the very beginning” says Calle Almedal of UNAIDS.

## Lessons learned: making the partnership work

### 1. Attitude

It was generally agreed that without the right attitude on both sides, the partnership would have faltered. Essential are:

- Mutual respect and consideration. Flavell: ‘There is no place for power play in this relationship’
- Openness: GNP+ said that the Federation was open about its past failures to tackle the reality of HIV/AIDS, and the fact that ‘it had AIDS’.
- Professionalism
- People listen to each other
- Ability to take risks and to experiment – ‘learn by doing’

### 2. Managing the organizational fears, stigma and discrimination

When the concept of the partnership with GNP+ was first presented within the Federation, it met with considerable opposition, based on fears and anxieties, stigma and discrimination. Bermejo and his team had to develop a conscious strategy to deal with this.

Initial contacts with GNP+ had deliberately been done with a low profile and little noise. In early discussions with senior management and governance, a process of milestones and engagement was agreed, including test cases that would decide whether to continue or not.

Bernard Gardiner, the person within the Movement with the most experience in working with PLWHA, was loaned by the Australian Red Cross Society to the Secretariat to work on the UNGASS side-event and manage the initial phases of the partnership. He understood the culture – and therefore fears – of the Federation and its people, at the same time had experience of the working style and aspirations of PLWHA organisations. His brief for the side-event was to ‘work for both the Federation and GNP+’. This meant pushing inside the Federation for space for the partnership -

for example, ensuring that there was equal space for GNP+ quotations in Federation press releases, and discussions about how partnership with an activist organization could work given the Movement's Principles of impartiality and independence. Gardiner was also a member of the HIV Governance Group, and a National Society delegate to Federation's General Assembly in 2001. This all helped to overcome the feeling of some Federation staff that Gardiner was too close to GNP+. It also made sense that soon after he was appointed Manager of the HIV Global Programme at the secretariat.

The team worked to create tools and opportunities for discussion of the partnership, and to further it. The video 'Living with...' had a considerable impact and helped to create organizational change of attitude and behaviour. Any organization planning to follow the example of a partnership with PLWHA should consider making such a video, especially for internal use. Events such as Barcelona, Berlin, UNGASS and Federation Board meetings were used to further understanding and strengthen the policy base around the partnership. In the same way, public commitments at public events by leaders were used to gain and retain that commitment. This was vital in ensuring that the Federation remained focused on HIV/AIDS during a period when there were many leadership and management changes.

It was also important early on to develop and support people that could best bridge the partners – people living with HIV/AIDS such as Dorothy Odhiambo and David Mukasa.

### **3. There is an urgent need for further capacity building**

Capacity building is needed in both organizations at all levels – of personnel, expertise, experience and funding, though especially of personnel and funding for PLWHA networks which are very young in terms of organizational development. The lack of capacity in PLWHA networks makes it less easy for them to participate in a meaningful and equal way as partners. The Red Cross and Red Crescent National Societies need to build up their expertise and experience in HIV/AIDS, and in many cases to formulate a clear strategic plan for a response to the epidemic.

The PLWHA networks need support to develop skills in running organizations, advocacy, public speaking, communications, and fund raising – and to reach out to more people. Hourcade stressed the need for a second generation of leadership. 'Membership of PLWHA organisations needs to be much more representative of the society it comes from. We need to build a bridge between international clout and the grassroots, the real world. Our volunteers are the real world, that is where you find diversity'.

Both Bermejo and Gardiner from the Federation believe that they should be doing more to strengthen GNP+ networks for the partnership to continue and to be sustainable. Gardiner broached the possibility of UN Theme Group funding for country level PLWHA groups, so that the groups maintain an independent voice and can get on with building capacity. He said: 'We want to avoid any sense of capture of the groups, as that's not a real partnership.'

### **4. There is a vital need to reach the grassroots**

Patrick Couteau and others argue that the partnership will not be fully effective until it is working through the branches of the National Societies, at grassroots level. The partnership can only evolve if both partners capacitate grassroots projects. Both Couteau and Bermejo had hoped that the manual *Positive Development* would have been used to achieve this, to set up support groups and empower PLWHA. The Federation has supported the translation of *Positive Development* into a number of languages.

Couteau: '*Positive Development* is a beautiful tool for empowering so why are we not using it?'

Bermejo said he had always expected that the Federation's machinery would swing into action with the manual and its programmes. He saw a parallel with First Aid training. There is clearly a need to reach out to more PLWHA in rural areas, where no support groups or health services exist. A clear strategy is needed to nurture and facilitate field engagement, said Bermejo.

### **5. Sustainability**

The successes of the partnership are due in large part to the commitment and hard work of a small number of charismatic and visionary individuals from GNP+ and the Federation. This is not unusual for such a pioneering venture; it is probably the only way it could have worked. But if the partnership is to develop, become less 'fragile' and be sustained, then it has to become more 'institutionalised' and less dependent on a few people. It is also important to build on and increase joint programmes that will keep the partners together.

Dorothy Odhiambo has called for the need to 'create sustainable approaches and activities that each partner can incorporate into their day to day response to the epidemic. For example, the development of joint work plans with specific goals to achieve as in the case of NAP+ and the RDN, joint capacity building forums for both the National Societies and networks or groups of PLWHA.'

### **6. Some practical issues have to be resolved**

Managers such as Francoise Le Goff, head of the RDN, said that operationalisation of the partnership has at times been extremely difficult. For example, she cited the issues of health insurance, travel insurance for PLWHA and the responsibilities at conferences for PLWHA who may become sick. She believes that senior management in Geneva don't know or don't understand the realities of implementing the partnership. 'We are constantly learning by doing.' She stressed that budget issues are unclear.

Bermejo agreed that he and his colleagues at the Secretariat had not been aware of how much effort it would take in the field, and hadn't resourced it properly.

Couteau also called for more flexibility in policies and procedures concerning staffing and employing PLWHA. 'The virus doesn't like stress and people then become ill,' he said. 'We have to be more flexible about our procedures.'

There was also a call for more clarity of direction and purpose and expected outputs from partners. Some people would like to see very clear terms of reference, with a sound description of what the partnership is about.

However, in Geneva, both Bermejo and Gardiner defended the lack of an official Memorandum of Understanding, arguing that it would have been too limiting on both sides. Gardiner explained: 'It's a living partnership, working on the basis of trust. PLWHA have to recognise limitations of what the Red Cross can do - for example, some humanitarian advocacy but most political work is done quietly behind closed doors.'

### **7. Dangers of exploitation**

There is a risk that some people living with HIV/AIDS will be used as volunteers by National Societies, for roles where they should really be paid and properly acknowledged. Not only is this unjust but it could be counter-productive in the long run to the partnership, and to development of volunteer involvement. The Movement already has problems attracting volunteers in many countries.

### **8. Expectations: differing?**

There is at times a gap between the partners in their hopes and expectations, especially at country level. One of the challenges of the partnership is that it brings together people whose needs and priorities are different. For example, explained Odhiambo in a report on the partnership, PLWHA need drugs, adequate nutrition and social support for their day to day survival. Any partnership that does not directly or indirectly address these needs might not readily receive adequate support from these groups. But the Federation can only, as a volunteer based organisation, play a small part in directly providing services. More allied to its mandate is to advocate for governments to improve their response and access to care and treatment. 'However, it has been observed that strong linkages have been created where there is congruency of strategy, purpose, values, communication between partners and commitment to the partnership,' explained Odhiambo in a report on the partnership.

Communication is essential to ensure that both sides understand what they can offer. Federation people have felt that PLWHA sometimes have unrealistic or impossible expectations of them – for example, the issue of blood in Honduras. On the other hand, PLWHA have found that the reality of their lives is not always understood by the NS.

The major issue, as stressed in this report, is access to drugs – both for opportunistic infections and anti-retroviral therapy. The lack of care and treatment for PLWHA will be a major barrier to the development of the partnership in many countries. Many PLWHA cannot function effectively without these drugs and so cannot sustain their responsibilities in the partnership. Nor will PLWHA, struggling with their day to day survival, be encouraged to volunteer for the Federation, as is needed for an effective partnership. The proposed fund will go some way to meet this requirement from PLWHA but not wholly. There is a need for further Federation advocacy to government and donors.

## **Conclusion**

The partnership, though young and still developing, sets a vivid and powerful example for others to copy. The Federation has been almost painfully honest about its internal struggles and contradictions. It is showing how standing by its humanitarian principles can make the world a better place for PLWHA, and thus provide a more effective response to the epidemic. It is indeed 'walking the talk'. It throws up a challenge to other organisations such as faith-based ones that would claim to share the same humanitarian principles. GNP+ and its networks have shown wisdom and maturity in the way they, the activists, have wholeheartedly embraced working with such a traditional organisation as the Federation. At every level where the partnership is working, there is warmth and affection, mutual respect and friendship.

The partnership also supports what has been known for some time about the most effective response to HIV/AIDS – the importance of leadership, community mobilisation and, of course, of the genuine participation of PLWHA.

**'Building more partnerships with People living with HIV and AIDS is the surest and fastest way to stem the epidemic and bring much needed support to vulnerable members of the community.' Francoise Le Goff, Head of Regional Delegation in Nairobi, speaking at ICASA 2003**

## Annex: from the UNGASS declaration of commitments

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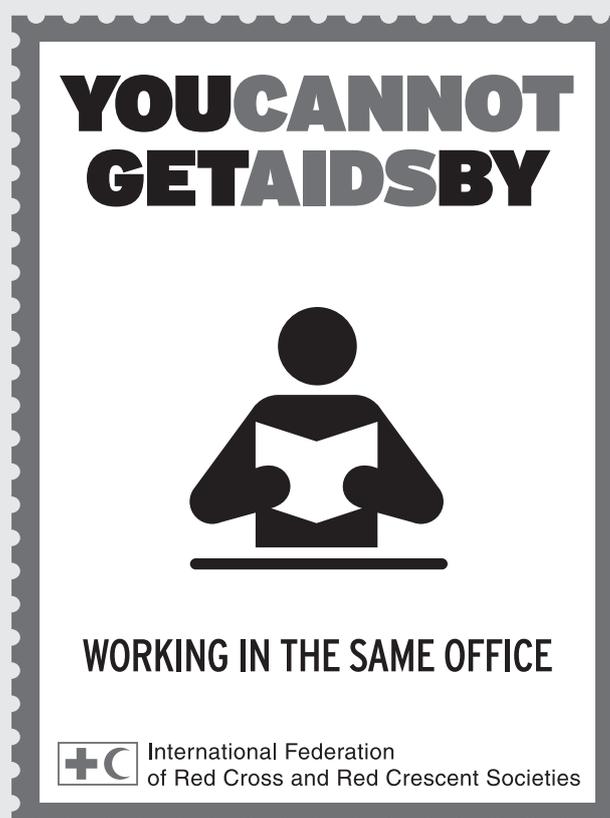
The United Nations Declaration Commitment on HIV/AIDS provides the guiding framework for UNAIDS action. Promoting partnerships among various stakeholders is reflected within the leadership section of the Declaration of Commitment.

In particular, it calls for complementation of government efforts by the full and active participation of civil society, the business community and the private sector through:

- Establishing and strengthening mechanisms that involve civil society, the private sector, faith based organizations (FBOs) and people living with HIV/AIDS at all levels;
- Encouraging and supporting local and national organizations to expand and strengthen regional partnerships, coalitions and networks;
- Full participation of people living with HIV/AIDS, those in vulnerable groups and people mostly at risk, particularly young people;
- Addressing issue of stigma and discrimination.

UNAIDS works to promote partnerships among a diverse and broad range of civil society members. This calls for increases in both the number of new actors as well as in new ways of working that facilitate the increased response capacity of civil society through strategic partnerships with all sectors at all levels.

With the momentum generated by the UN Special Session on HIV/AIDS, the main challenges are to, one, sustain and deepen involvement of those contributing and critical to the response such as PLWHA organizations and, two, move beyond the “converted” and involved sectors, such as AIDS organizations, and reach out to a broad range of sectors/actors such as development NGOs, business and other non-traditional AIDS philanthropic entities to support the work.



## Annex: the Denver principles

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### **Created by the Persons With AIDS Coalition at the Second National AIDS Forum in Denver 1983**

We condemn attempts to label us as “victim,” which implies defeat, and we are only occasionally “patients,” which implies passivity, helplessness, and dependence upon the care of others.

### **We are “people with AIDS.”**

#### **We recommend that health care professionals:**

- 1 Who are gay, come out, especially to their patients who have AIDS.
- 2 Always clearly identify and discuss the theory they favor as to the cause of AIDS, since this bias affects the treatment and advice they give.
- 3 Get in touch with their feelings (fears, anxieties, hopes, etc.) about AIDS, and not simply deal with AIDS intellectually.
- 4 Take a thorough personal inventory and identify and examine their own agendas around AIDS.
- 5 Treat people with AIDS as whole people and address psychosocial issues as well as biophysical ones.
- 6 Address the question of sexuality in people with AIDS specifically, sensitively, and with information about gay male sexuality in general and the sexuality of people with AIDS in particular.

#### **We recommend that all people:**

- 1 Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us, separate us from our loved ones, our community, or our peers, since there is no evidence that AIDS can be spread by casual social contact.
- 2 Do not scapegoat people with AIDS, blame us for the epidemic, or generalize about our lifestyles.

#### **We recommend that people with AIDS:**

- 1 Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda, and to plan their own strategies.
- 2 Be involved at every level of AIDS decision making and specifically serve on the boards of directors of provider organizations.
- 3 Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
- 4 Substitute low-risk sexual behaviors for those that could endanger themselves or their partners, and we feel that people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

#### **People with AIDS have the right:**

- 1 To as full and satisfying sexual and emotional lives as anyone else.
- 2 To quality medical treatment and quality social service provision, without discrimination in any form, including sexual orientation, gender, diagnosis, economic status, age, or race.
- 3 To full explanations of all medical procedures and risk, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment, and to make informed decision about their lives.
- 4 To privacy, to confidentiality of medical records, to human respect, and to choose who their significant others are.
- 5 To live and die in dignity.

## Annex: Barcelona Declaration

### Developing leadership to scale up the AIDS response

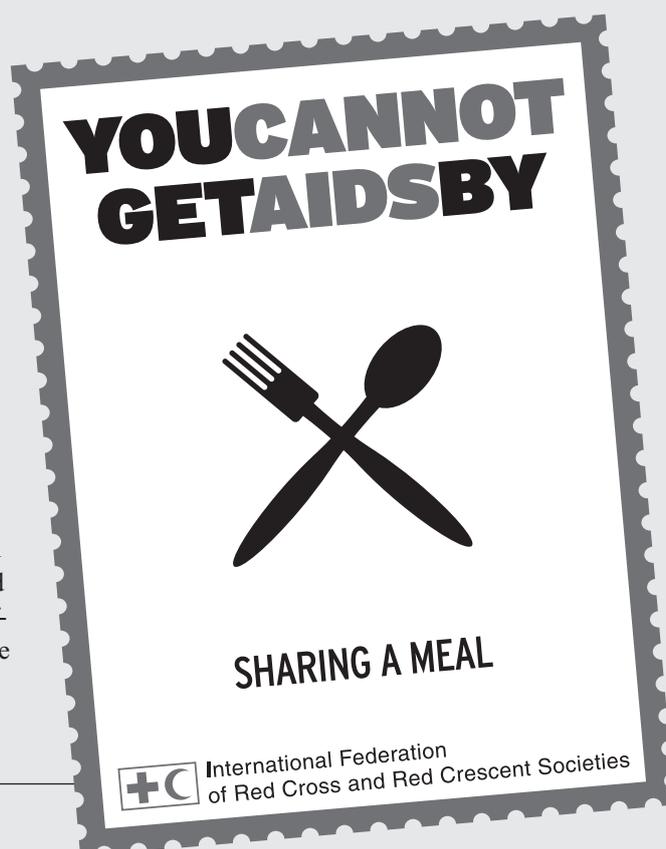
#### The Barcelona Commitment

The HIV/AIDS epidemic is having a devastating effect on the lives of millions of people and reversing economic gains of recent decades; it represents a global humanitarian disaster. This has already been recognised by many Red Cross Red Crescent declarations and resolutions.

The XIV International AIDS Conference in Barcelona has highlighted the importance, the urgent need of leaders to articulate successful community responses to HIV/AIDS.

Red Cross Red Crescent National Societies, with a respected name and emblem and a vast network of volunteers reaching into almost every community in the world have a crucial role to play: to develop and support those that can lead the local responses. At the Barcelona Conference we have heard and seen many examples where this has been done successfully and taken to scale. Inspired by them, we recognise that public utterances are important, but so is setting an institutional commitment. Ready to take on this responsibility we commit to the following action:

- **Policy commitment:** We will promote within our boards decisions that institutionalise our support to community responses to HIV/AIDS as a top priority for our National Society. Reducing household vulnerability to HIV/AIDS at home and/or abroad is a global humanitarian priority.
- **Planning / programme development:** We will promote and create the right environment for systematic and accountable HIV/AIDS planning to achieve measurable goals and targets. Lack of resources can be no excuse for lack of planning and effective action cannot take place in a vacuum.
- **Create capacity:** We will strengthen human resource AIDS competency through training, recruitment and partnerships. We commit to accelerated development of the National Society capacity at the local level required to support communities engaged in the response to the epidemic.
- **Holistic response:** the community response to AIDS can only succeed in the presence of appropriate prevention, care, support, treatment and in an environment that respects and includes people living with HIV/AIDS. The Red Cross Red Crescent must, and can make a significant contribution in each and everyone of these areas.



- **Stigma and discrimination:** We will work to reduce the stigma associated with HIV and AIDS and to protect human rights through personal and political advocacy and the promotion of policies that prevent discrimination and intolerance. We will publicly stand by people living with HIV-AIDS, and promote the positive contribution they can and are making to prevention and care work.
- **Reach out to those that are more vulnerable:** We will take innovative approaches to enable our National Society to address, through advocacy and/or services, the needs of those most vulnerable to infection and especially individuals and families living with, orphaned or made otherwise vulnerable by HIV-AIDS. This includes young women, refugees, internally displaced people, persons separated from their families due to work or conflict, commercial sex workers and their clients, injecting drug users and their sexual partners and men who have sex with men..
- **Workforce policy and involvement of people living with HIV/AIDS:** We will develop a policy to deal with HIV/AIDS in the workforce and take specific measures to promote the full participation of people living with and affected by HIV/AIDS in the response to the epidemic. The survival of our organisations in hard hit countries is threatened by the impact of AIDS on our volunteers and staff.
- **Partnerships:** We commit to actively support the development of partnerships required to address the epidemic— in particular, those required to improve access to essential information, services and commodities. We acknowledge that only broad-based partnerships can curb the epidemic; we shall actively seek to engage government authorities, community based organizations and people living with HIV/AIDS in a coordinated response.
- **Integration and mainstreaming:** We will strive to develop National Society policy initiatives to incorporate HIV/AIDS at the highest level. Responding to AIDS undoubtedly requires a leadership role from health departments and services. But it also requires far more, integrating HIV/AIDS into all relevant policies and programmes, including youth, first aid, social services and disaster management. This in turn requires a policy initiative at the highest level that we commit to drive

**We, Red Cross and Red Crescent leaders gathered at the XIV International AIDS Conference in Barcelona have had the privilege to witness first hand the global impact of AIDS.**

**We personally commit to achieve the objectives stated in the Barcelona Commitment and provide a progress report to the HIV/AIDS governance group through the Secretariat by June 1st 2003 so that it can report on progress made to the Board and General Assembly meetings taking place towards the end of 2003.**

**Signed in Barcelona on July 12, 2002.**

The Joint United Nations Programme on HIV/AIDS (UNAIDS) brings together eight UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank.

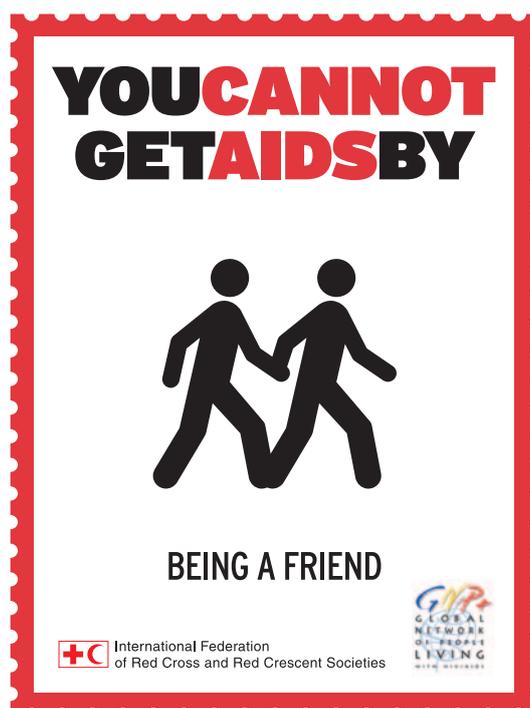
UNAIDS, as a cosponsored programme, unites the responses to the epidemic of its eight cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV/AIDS on all fronts. UNAIDS works with a broad range of partners—governmental and nongovernmental, business, scientific and lay—to share knowledge, skills and best practices across boundaries.

## UNAIDS • BEST • PRACTICE • COLLECTION

### The UNAIDS Best Practice Collection

- is a series of information materials from UNAIDS that promote learning, share experience and empower people and partners (people living with HIV/AIDS, affected communities, civil society, governments, the private sector and international organizations) engaged in an expanded response to the HIV/AIDS epidemic and its impact;
- provides a voice to those working to combat the epidemic and mitigate its effects;
- provides information about what has worked in specific settings, for the benefit of others facing similar challenges;
- fills a gap in key policy and programmatic areas by providing technical and strategic guidance as well as state-of-the-art knowledge on prevention, care and impact- alleviation in multiple settings;
- aims at stimulating new initiatives in the interest of scaling up the country-level response to the HIV/AIDS epidemic; and
- is a UNAIDS interagency effort in partnership with other organizations and parties.

Find out more about the Best Practice Collection and other UNAIDS publications from [www.unaids.org](http://www.unaids.org). Readers are encouraged to send their comments and suggestions to the UNAIDS Secretariat in care of the Best Practice Manager, UNAIDS, 20 avenue Appia, 1211 Geneva 27, Switzerland.



Joint United Nations Programme on HIV/AIDS

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