
IGAT HOPE INC.

National Conference for People Living with HIV
Papua New Guinea (PNG)

November 2008
Conference Report



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Background to the conference

The first ever national conference for people living with HIV (PLHIV) in PNG was held at the Holiday Inn, Port Moresby, from Sunday 2nd November to Thursday 6th November 2008.

The conference was held because Igat Hope thought it important that people living with HIV across PNG come together. Together, PLHIV would be able to share experiences of being HIV-positive and offer each other peer support. For some of the delegates it was the first time they had been able to talk with lots of other people with HIV and this helped overcome some feelings of isolation.

The conference was also planned to help PLHIV learn about issues relevant to their health and lives. There was a heavy focus on learning and skills building.

The conference was hosted by Igat Hope, under the leadership of President Helen Samilo. It was organised by a sub-committee of Igat Hope including Maura Elaripe Mea, Rona Nisio, Don Liriope and Peter Momo.

The opening session included speeches from past-President Peter Momo and current President Helen Samilo, followed by a presentation from AusAID representative Anne Malcolm, and a keynote address from the Chairman of the Special Parliamentary Committee on HIV/AIDS, Mr Jamie Maxton Graham.

The event was generously funded by AusAID's PNG-Australia HIV/AIDS Program. AusAID provided all of the financial resources for the event, and AusAID staff participated in many sessions.



Additional support was provided through the Australian National Association of People Living with HIV/AIDS (NAPWA). NAPWA provided support to Igat Hope in the development of the conference program, and a consultant employed by NAPWA, Dr Susan Paxton, provided on the ground assistance with organisation of the event. Susan worked with the Igat Hope conference sub-committee and the secretariat to develop the program, organise speakers and arrange conference logistics. Susan also undertook the conference evaluation.

NAPWA also funded the participation of two peers, John Trigg and Kenn Basham. John and Kenn helped support the conference organisers and shared stories with conference delegates based on their long histories of involvement in the Australian positive people's movement.

NAPWA's sponsorship also included funding a facilitator, Tim Leach, for the conference's session on future structure, and for the AGM.

Support for the event was also provided by the Lamana Hotel, Port Moresby.





Opening address to the conference by Igat Hope President, Helen Samilo

I bring greetings and welcome you all to this official opening of the 1st PNG National People living with HIV Conference in Port Moresby today.

This weeks event will mark the 1st of its kind historical 3 days conference for all people living with HIV and AIDS in Papua New Guinea. This event reminds me of the hardships that people living with HIV and AIDS are facing today, since HIV was first diagnosed in our country Papua New Guinea 21 years ago.

The long journey since then, that has brought us here, today together, marks significance of that time that each person living with HIV and AIDS have taken, as a



challenge to survive, not by the choices of men, but by their strong will and determination that is driven in us to rise to the ever challenging and changing world. To live like the rest of the world who are also sharing the same challenge to address the AIDS epidemic, and are still looking for cure to this day. Igat Hope Inc is also rising to stand in Papua New Guinea to face the challenge and seek options to suit the people living with HIV and AIDS it represents.

We, the people living with the HIV who are here today, and those who are our colleagues and partners in this fight; have survived the AIDS epidemic, despite social, spiritual and economical challenges. Though we are not fully equipped with the HIV program interventions, health facilities, sustainable availability of Antiretroviral Treatments in the other parts of Papua New Guinea, Local HIV expert doctors and the provision of basic opportunistic infection treatments, we have lived by GOD'S GRACE and strength to see this day of our gathering.

This event also reminds me of our late brothers and sisters, namely...

1. Joseph Berem
2. Max Mea
3. Ruth Wati
4. Rodney Kewa
5. Ferguson Laho
6. Etcetera

And children who have gone to live with the lord, I offer my prayers and thank them for paving a pathway, for us who are alive today to see that living with the HIV is not an easy thing. It comes with greater responsibilities, true love, care and support.

This event, reminds me again of those times, 7 years ago where few people living with HIV and AIDS would come together despites situations, whether there was stigma and



discrimination, bus fares, food or availability of transport for drop off after the gathering. People living with HIV would just come together to share stories & experiences because HIV was a new disease in our country, Papua New Guinea. And out of that small group, IGAT HOPE INC was born, today a National Network of People living with HIV, with the help of prominent people who have given great support and assistance.

I would mention their names and the list would go on.....and consume time, but their names are always at the deepest part of Iगत Hope Inc heart.

Prominent people to whom IGAT HOPE INC still seeks advice from to this day, after 7 years of survival, and they are:

- Dr Nii K. Plunge – Former UNAIDS Country Coordinator
- Dr Susan Paxton – Advisor to Asia Pacific Network of People living with HIV and AIDS
- Mr David Passirem – National AIDS Council Advisor Care & Counselling
- Ms Maire Bopp DuPont – Executive Director to Pacific Islands AIDS Foundation
- Mr John Rock – Advisor to Asia Pacific Network of People living with HIV and AIDS
- Ms Sharon Kelly – Team Leader to former project of AUSAIDS, NHASP
- Ms Sharon Walker – NHASP Care & Counselling advisor
- Ms Bessie Maruia
- Ms Jaclyn Badcocok
- Ms Margaret Lokoloko

Organizations that provided shelter by providing care and support to promote the forming of this National Network of Positive People in PNG are:

- Salvation Army, Ela Beach – big thank you to Keagii for always providing us with good nutritional food



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- Anglicare STOP AIDS – for always empowering people living with HIV to have confidence in them to face the challenge of the AIDS epidemic.
 - PNG Red Cross & Australian Red Crescent Society – for starting a conversation and putting ideas together technically for Igat Hope Inc to be well established and is still in the process to be....
 - Family Health International – for testing the waters with the first project with Igat Hope Inc

And the list goes on and on...

These people, despite their professional work commitment, have given their time and skills to establish the foundation of Igat Hope Inc. And I, as the President of Igat Hope Inc on behalf of the members, provincial and local networks of people living with HIV and AIDS, would want to commend you for your contributing efforts to the making of Igat Hope Inc.

In closing, Today, this 3 days conference themes for each day will greatly help Igat Hope Inc to see it's aim and vision clearly in terms of planning for the next 3 years to prove it's leadership, and setting up it's structures as a coordinating mechanism for the National Network of People living with HIV and AIDS in Papua New Guinea.

Though Igat Hope Inc is only 7 years old, and look, it has already provincial and local networks of people living with HIV and AIDS in the provinces, because there is a greater need that needs to be assisted to the ever changing world, that would now want to live with this AIDS epidemic.

Igat Hope Inc thanks and also acknowledges the representatives of those positive networks that are here today, and also our colleagues, partners to whom Igat Hope Inc greatly rely upon for advice, assistance and directions. May these 3 days be a blessing



and inspiration to those of you who will be attending and contributing meaningfully. Your participation and contribution will assist Igat Hope Inc to plan well for the future. Thank you very much for your time in coming to participate in this conference. Your contributions will be highly appreciated.

Thank you very much, and GOD BLESS U all

Helen



Opening address to the Conference by Anne Malcolm, AusAID's PNG-Australia HIV and AIDS Program (Sanap Wantaim)

- I am very pleased to make some remarks at this the opening ceremony of the first National People Living with HIV and AIDS (PLHIV) Conference in PNG. Australia recognises that Papua New Guinea has a serious HIV epidemic and is committed for the long term to assist PNG to scale up and more effectively manage its response to HIV through the Papua New Guinea-Australia HIV and AIDS Program (also known as Sanap Wantaim). Our approach is to work through and support local institutions, to build on knowledge and systems that are already there and to strengthen partnerships between organisations that can build skills and capabilities of people for a more effective response at the local level.
- We know that infections are increasing and that we are seeing many more people living in rural areas testing positive for HIV. We all know that unless we act quickly with effective interventions and adequate resources that PNG will experience an epidemic that will have devastating effects on the economy and communities. PNG is committed to achieving the goals of universal access by 2010. Critical to our success in this is improving the inclusion and participation of people living with HIV and AIDS in all aspects of programming and implementation of national and local responses.



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- This conference is an important step in making the Greater Involvement of People Living with HIV and AIDS (GIPA) a reality in the national response to HIV. As the sponsor of this conference, AusAID recognises that ongoing dialogue between those infected and affected by HIV and AIDS and stakeholders, is vital to achieving the meaningful participation of PLHIV in the national response.
 - The PNG-Australia HIV and AIDS Program or Sanap Wantaim is committed to enabling the greater participation of PLHIV in the national response and the identification, support and strengthening of PLHIV networks throughout PNG. The program has recently recruited a GIPA Advocacy Officer to work in this area. In the last 2 months several regional and provincial meetings have been held to bring together PLHIV groups to equip them with skills to become more involved in local responses. These meetings are just the starting point for bringing people together. We need to continue to work on ways to increase the visibility of these groups and find ways to integrate these groups into local activities. This includes finding ways to adequately resource local groups to provide leadership and build capacity for better governance, management and accountability.
 - We have also been supporting a partnership between the Australian National Association of People Living with HIV and AIDS (NAPWA) and Igat Hope. This partnership has assisted to strengthen the operations of Igat Hope and the training of positive people to be effective communicators within the community.
 - Igat Hope is to be commended for facilitating this conference. This conference is aimed at building networks among positive people that are sustainable, accountable, transparent and capable of effectively representing their members.
 - A national network of PLHIV organisations in PNG is yet to be realised. The Papua New Guinea-Australia HIV and AIDS Program [Sanap Wantaim] agrees with the recent assessment of the Independent Review Group and considers this conference an ideal opportunity to work towards making a truly national network of PLHIV in PNG, a reality.



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- Finally, for those of you attending the conference, I encourage you to participate to your fullest and wish you a productive week. I am optimistic that the outcomes of this conference will provide vision for the future and engender unity amongst those of us who are affected by HIV in this country.

Background

- Papua New Guinea's (PNG) HIV epidemic has reached an estimated prevalence rate of 1.61 percent. The Government of PNG considers the epidemic a development issue and has developed the NSP to be the centrepiece of the national response.
- The Australian Government is taking the epidemic seriously and is supporting the Government of PNG, civil sector organisations and other stakeholders in the response, through the PNG - Australia HIV and AIDS Program (Sanap Wantaim) managed by AusAID.
- NSP Focus Area 6 aims to sustainably support a conducive environment for families to care for and support people infected and affected by HIV. The effective integration of the GIPA principle into the national response is vital to creating that environment.
- The recent Independent Review Group (IRG) report notes a priority for Focus Area 6 as "identifying, supporting and strengthening of groups of PLHIV in each province to run an empowered network" and that "a national network of organisations of PLHIV does not yet exist".
- The IRG report encourages PLHIV and their organisations attending this conference to develop a national networking strategy with the full support of NACS and development partners.
- AusAID has sponsored this important forum and remains committed to supporting the greater involvement of people living with HIV in PNG's response to HIV. We commend Igat Hope (Inc) for their tireless efforts to facilitate this conference.



The Program

The conference played an important role in providing information to people with HIV about treatments and other ways of looking after their health. Delegates were offered a mix of plenary sessions, smaller workshop sessions and skills building sessions. Topics covered included:

- Access to treatment, care and support
- HIV surveillance
- Epidemiology
- Research
- Knowledge management
- Obtaining funding
- Voluntary counselling and testing (VCT) and treatment
- Positive prevention
- Positive men
- Positive women
- Reproductive health
- Home-based care
- The Greater Involvement of People Living with HIV/AIDS (GIPA) principle
- Gender policy
- Leadership, partnership and coordination.

The conference allowed people to learn about different aspects of the national HIV response in PNG from lots of different presenters. Guest presenters came from a range of agencies and organisations including:

- AusAID
- The National AIDS Council



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- Marie Stopes
 - Family Health International
 - Poro Sapot (Save The Children in PNG)
 - NAPWA
 - WHO (PNG)
 - Port Moresby General Hospital's Heduru Clinic
 - PNG Health Department
 - Australian Research Centre in Sex Health and Society
 - PNG Institute for Medical Research
 - Igat Hope
 - Igat Hope (Milne Bay)
 - Tru Warriors
 - Good Samaritan Centre
 - PNG Association of Civil Society Organisations.

Igat Hope also thought it important that people from different provinces be able to share ideas about what they want from a national organisation. For this reason, a big part of the program was devoted to discussions about the future of a national PLHIV organisation in PNG.

Igat Hope arranged for its AGM to occur the day after the conference officially closed. Igat Hope hoped that many conference delegates would be able to stay around and observe the AGM so that they could see how Igat Hope operates. For many conference participants it was their first time at a formal AGM.



Who came to the conference?

Igat Hope took responsibility for making sure there was representation from as many different provinces as possible. Board members used their networks to help locate people with HIV in different provinces and twenty provinces were represented. The aim was to have two delegates from each province and this target was achieved with most provinces. Igat Hope tried to make sure there was a gender balance at the conference so generally selected one man and one woman from each province.



Where possible, Igat Hope invited PLHIV to represent their provinces. This was not possible in all provinces and in these cases people working *with* PLHIV were invited.

Delegates included 41 people from provinces outside of NCD. Thirty people from Igat Hope Port Moresby attended each day (although it was a different 30 each day as demand was so high). Spaces were allocated for seven HIV-positive men who have sex with men and nine sex workers. A total of 87 delegates attended the conference each day.



Conference themes

As the conference program (Attachment 1) shows, lots of different issues were covered at the gathering. Each presentation was followed by questions and comments from participants, and there were many lively discussions. There were many issues where people did not agree, but there were also many times where people agreed. Agreements often led to session recommendations (Attachment 2).

The major themes of the conference are discussed below.

Theme 1: HIV training in PNG

There was discussion about HIV-related training in PNG. Participants agreed that there is lots of training going on. The training is done by lots of different groups. But participants did not always feel that the training was appropriate, or aimed at meeting the most important needs. People also thought that the trainings were often not what were needed by PLHIV. And even when trainings were appropriate for PLHIV it was not always possible for PLHIV to get into the training sessions.

Igat Hope has some expertise in the training needs of PLHIV, and some useful ideas about what HIV-related training is required in PNG. It was agreed that a bigger role for Igat Hope in helping shape the national training agenda would be a good outcome. Institutions and organisations responsible for HIV training are encouraged to seek advice from Igat Hope on what training is required and the best ways to deliver it.

Recommendation 1: We recommend that Igat Hope has a bigger say in deciding what HIV trainings are provided in PNG and where they are provided.



In particular it was agreed that there should be more involvement of PLHIV in designing and delivering home based care programs. It is not true that all home based care is provided for PLHIV by people who are not HIV-positive. In fact, a lot of home based care is provided by PLHIV themselves. This is especially common in cases where PLHIV have been abandoned by their families – often they have only other PLHIV to assist them. Igat Hope members often provide home based care and support to each other. People agreed that it was important that PLHIV be amongst each group of participants for home based care training.

It was also noted that the Greater Involvement of People Living With HIV/AIDS (GIPA) principle requires participation by PLHIV at every level of the response – not just as participants in training sessions but also as designers and deliverers of training courses.

Recommendation 2: We recommend that PLHIV be more involved in the design and implementation of home-based care programs. Future home-based care trainings should train more PLHIV.

Theme 2: Using research to help develop understanding of PLHIV

The conference heard some interesting data about PLHIV from the Institute of Medical Research (IMR). Some preliminary findings from work by Dr Angela Kelly and her team at IMR were shared with the conference by Dr Susan Paxton, speaking on behalf of Dr Kelly. Participants agreed that the data did reflect the realities of life for PLHIV in PNG. PLHIV are often stigmatised and accused of behaviours which the data does not support. In fact the research showed that PLHIV are keen to manage the HIV infection through healthy living and to assist others. Participants thought that this picture would help



Papua New Guineans to understand PLHIV better and that this might help reduce stigma and discrimination.

Recommendation 3: We recommend that IMR's recent research on PLHIV and ART be widely distributed. Stories from the research should be shared widely, including through radio and theatre.

Theme 3: The HIV/AIDS Management and Prevention (HAMP) Act

It was agreed that while the HAMP Act is an important tool for PLHIV in PNG, to date is has not been well used. There was some frustration in not being able to use the Act to protect people with HIV from discrimination; instead it was only being used *against* PLHIV or those working on their behalf. Participants asked 'What is the point of having this Act if we are never able to use it to help us?' To overcome this problem, delegates thought more people should to be made aware of the Act and PLHIV needed to be helped to use it. It would also be important to find qualified people to provide legal representation for PLHIV wanting to use the HAMP Act.

Recommendation 4: We recommend that there be greater effort to help PLHIV understand and use the HAMP Act. We recommend the NAC work harder to implement the HAMP Act and to make sure village courts are aware of the Act. The Special Parliamentary Commission on HIV should support this work.

Theme 4: Men who have sex with other men (MSM) in PNG



Several participants at the conference identified as men who have sex with other men (MSM). These delegates told some stories of how they have experienced discrimination because of their sexuality. This discrimination has occurred when they have been trying to obtain care and support, so their health has suffered because of the discriminatory views of others. Conference participants agreed that this should not be the case. People agreed that all services should be free from discrimination. They also agreed that because discrimination against MSM is unlikely to disappear in the near future, there might be a need to have some services especially for MSM so that they receive appropriate care. Participants agreed that just because specialist services might be around that did not excuse other services for discriminating against MSM.

Recommendation 5: We recommend that MSM have better access to HIV care and support free from stigma and discrimination. Mainstream services should not discriminate against MSM. Some MSM specialist services may be needed.

Theme 5: HIV treatments, care and support

Conference participants talked about the importance of treatments, care and support. Many people told stories of having difficulty getting the care and support they need. One of the reasons for this is a lack of public support for care and support for PLHIV. This might be because of ignorance ('why would they need special care and support services?') or because of discrimination ('they don't deserve care and support services – they brought it on themselves'). Whatever the reason, people agreed it would be good to try and build community support for meeting the care and support needs of PLHIV. After all, HIV is everyone's business in PNG and all families will be affected in one way or another. PLHIV have the right to good care, and good care and support for PLHIV helps prevent transmission. Media and publicity campaigns are expensive, so small



organisations like Igat Hope could not pay for them. They could only be funded by government or major donors.

Recommendation 6: We recommend media and public campaigns that advocate for treatment, care and support for PLHIV.

Participants also heard about some cases of service providers offering care and support services which were not appropriate. In some cases the services provided were not what were wanted by local PLHIV. In other cases services were being provided with poor and occasionally discriminatory attitudes. Positive people should be involved in the design of services for PLHIV – this is an important part of the GIPA principle.

Workshop participants agreed that it would be good if service providers consulted with Igat Hope about how to deliver services. This means that Igat hope must have the capacity and expertise to assist service providers who ask for advice from the organisation.

Recommendation 7: We recommend that there be consultation between Igat Hope and partners who are providing care and support programs for PLHIV.

There was discussion about the availability of ART in PNG. Stories from around the country showed there was much improvement needed, particularly outside of Port Moresby. The ability of PLHIV to have their viral load monitored or to access treatments really varies depending on where they live. People shared stories of drug supplies running out. They also told stories of doctors and other health care workers who didn't really understand how the drugs should be taken, so were unable to give proper advice. There were also lots of stories about the state of the PNG health system, with people commenting that the system could not cope *before* HIV became a problem in PNG.



Now, with the increased demands for HIV-related services, parts of the system appeared close to collapse.

While people accepted there is a lack of resources for hospitals and the health care system in PNG, it was still agreed that some improvements could be made at no cost. PLHIV should be consulted about treatments, and the consultation should be meaningful. This is a low-cost change and would improve ARV roll-out and availability.

Recommendation 8: We recommend treatments be available from all accredited sites, with sustainability maintained. We recommend better access to CD4 count machines across PNG.

Recommendation 9: We recommend National Department of Health and WHO consult extensively with PLHIV, especially with treatment guidelines and treatment roll-out.

The IMR research showed some interesting data about the role of the churches in helping shape PLHIV attitudes to taking ART. The research showed a link between taking ART and membership of particular churches, so a supportive church environment might help PLHIV to stay on treatments. Churches that lower PLHIV self-esteem, or that suggest there is no earthly means of managing HIV, are likely to reduce the ability of PLHIV to start or stay on treatments.

Recommendation 10: We recommend that Churches in PNG support PLHIV and the treatment decisions that PLHIV take. We suggest Igat Hope seek a meeting with Church representatives to share the results of the IMR's recent research into PLHIV.



There is a need for much greater understanding amongst PLHIV of what ART can do to help people manage HIV. Most PLHIV in PNG do not understand the ways that treatments can assist them. Many PLHIV in PNG die because they have not had access to ART early enough, if at all. People agreed that this is unacceptable. Participants agreed that it is up to each individual to decide if and when to take treatments, but that everyone should have the choice and the information necessary to help them make the choice.

Recommendation 11: We recommend more treatments literacy trainings for PLHIV whether or not they are taking ARVs.

Theme 6: Participation

PLHIV involvement in decision-making is a bit hit and miss in PNG. PLHIV representatives are included in some important bodies, but they are also absent from some important bodies. Participation by PLHIV and representation of PLHIV are important. The national response must make this a focus of its efforts and must resource PLHIV participation.

Recommendation 12: We recommend that the National AIDS Council includes a PLHIV on its NSP Technical Working Group.



Towards a national representative structure

The conference focussed on the issue of how to ensure Igat Hope can truly represent PLHIV views from across the country. At present, and for many good reasons, Igat Hope's membership is made up of people who live in Port Moresby. The conference delegates talked about how this could be changed so that the organisation becomes more presentative of PLHIV across PNG. This will require Igat Hope to change its membership structure.

The conference broke into five smaller discussion groups: Southern, NCD, Highlands, Islands and Morabe. Groups then returned to talk together as a whole group. There was a lively discussion about ways forward – there were some disagreements but lots of agreement.

PLHIV organisations across PNG want to contribute and participate in Igat Hope. They want it to be the national voice for PLHIV issues. And they want Igat Hope to help them get stronger so that they can deliver help to their local members. The shared vision was for a strong national voice, which truly represents PLHIV from across the country. Regional, provincial and local PLHIV organisations would still have important roles helping their local members, but Igat Hope would speak at a national level on PLHIV issues.

Agreements about the way forward:

It was agreed that PLHIV organisations and groups at the conference:

- Recognise Igat Hope as PNG's national PLHIV organisation
- Want and expect 1 representative on the Igat Hope Board from each region in PNG
- Call on Igat Hope to coordinate the national PLHIV network
- Call on Igat Hope to recognise regional and provincial PLHIV groups, and to sign agreements (like memoranda of understanding) with these groups
- Want greater participation in major Igat Hope activities, such as organising conferences.



It was agreed that Igat Hope can strengthen other groups around the country in the following ways:

- By communicating well with other groups
- Supporting regional and provincial groups to be implementers of PLHIV programs
- Helping build the capacity of other PLHIV groups in areas such as GIPA and advocacy
- Supporting groups to develop constitutions
- Offering technical support
- Lobbying at a national level on issues affecting PLHIV
- Helping PLHIV groups to talk to each other.



What could be improved for the next conference?

As with any conference, not everything went according to plan. Some things might have been better handled, for example:

- Some scheduled speakers did not arrive to present. Next time, Igat Hope might take extra steps to confirm that speakers will attend. This might mean sending a confirmation letter and phoning them the day before they are due to present.
- The program did not arrive in time, meaning delegates found it hard to decide which sessions to attend.
- The Holiday Inn did not provide functional microphones. When they did work, there were problems with noise travelling between session rooms which were only divided by thin partitions.
- There were problems with transport and the provision of allowances – Igat Hope did not receive the logistical support it had hoped for.
- The issue of allowances needs to be revisited before the next conference. Expectations around receiving allowances created problems. Igat Hope's approach to payment of allowances was not to the satisfaction of the funders and may not be possible next time. In particular, allowances for attending an AGM are highly problematic and should not occur in the future. It will also be easier to provide all meals rather than give people an allowance for meals. Participants from Port Moresby should receive reimbursement for travel costs only and not an allowance.
- The AGM was not as well prepared as it might have been. No doubt, it was difficult to organise the event on top of such a busy conference, but a lack of preparation in some areas made the event quite difficult.



Conference Evaluation

The first national conference for people living with HIV in PNG was a very productive forum. It brought HIV-positive people and some of their supporters from each of the twenty PNG provinces together and provided a unique networking opportunity with peers from different regions. The conference also enabled participants to gain new skills and information, and to develop a forward, more-inclusive direction for Igat Hope.

The mix of plenary presentations and workshops for the first two days worked well for people who attended all three days. Many participants said they really appreciated the group work and wanted more of it. Several Port Moresby participants found it frustrating to attend for one day only. The response to the sessions indicated positive people's thirst for up-to-date information about a range of issues including HIV treatments, care, advocacy and grant applications.

Considering the technical challenges posed by the venue (the Holiday Inn), particularly in relation to non-working microphones, the sessions in fact ran very smoothly, and the Igat Hope Board, Secretariat Coordinator and NAPWA technical support team deserve congratulations for managing to conduct a relatively smooth, worthwhile conference that generated goodwill between key players and helped to strengthen the role of people living with HIV in the response. The decision to include regional representatives in the Igat Hope Board will only strengthen the national network and NAPWA could offer assistance to make the necessary constitutional changes. In future conferences, lines of authority can be clearly defined.



Participants' feedback

All quantitative questions scored between 4.3 and 4.7, on a scale of 1 to 5, indicating **high satisfaction** with the conference. Participants found **Monday morning** (Access to treatment, care and support), **Tuesday afternoon** (reproductive health, home-based care, GIPA and gender) **and Wednesday afternoon** (discussions and recommendations on the future of Igat Hope as a national organisation) **sessions most useful** and easy to understand.

Session	Mon AM	Mon PM	Tue AM	Tue PM	Wed AM	Wed PM
Was useful	4.7	4.6	4.6	4.7	4.6	4.7
Understood	4.5	4.4	4.4	4.5	4.3	4.6
Can help my network	4.6	4.5	4.4	4.6	4.6	4.5

What people **liked most** (cited by >10 participants):

- Recommendations on way forward with Igat Hope structure
- Plenary on ARV treatment
- Discussions with all participants/ group work
- Home based care session
- GIPA advocacy workshop

Sessions people found **most useful** (cited by >10 participants) are:

- Small grants
- Home based care
- GIPA advocacy
- Knowledge management
- Information on ART



Many participants said they found all the sessions useful as they were learning many new things.

Majority of suggestions for **improving** the conference were:

- More days
- More group work and discussions
- More talk in pidgin
- Providing handouts
- Microphones that work
- Learning more about what other networks are doing in other provinces

Other comments: (quotes from evaluation forms)

Criticisms

- Don't speak so fast
- My body feels pain – the air con is not good for me
- Mobile phones off
- More space
- Give topics to speakers beforehand
- Follow the programme if it is drafted
- The next time a conference is held it must be held according to the program
- This being the first conference I was not happy to be present only one day. I don't even know what the sessions were on the other two days. I am very disappointed.
- Every member of Igat Hope has to participate fully for the whole three days
- Let everyone give their views
- Improve lunch because some miss out
- It seems people from Port Moresby are only interested in themselves
- I want to fight HIV not people with HIV
- Finished late



Suggestions

- Let's have a positive living advocacy photo of all participants who want to advocate
- Bring ideas for mass VCT tests to control HIV spreading
- Do condom demonstration to fully empower PLHIV
- More PLHIV involved
- Next time please let's have a vote when there is a question to answer eg: gender balance on Board
- Get trainers like Dr Paxton to facilitate sessions according to our level of understanding
- Make sure everything is set ready for the day's session
- Assess knowledge level of each participant
- Please provide additional resource material like samples on PLHIV associations, constitutions, policy drafts, promotional carrier bags/ T-shirts on positive living; please provide conference photos for participants on CDs and send to provinces.
- More ToT workshops in home based care to involve more PLHIV
- Select Board Members from all over PNG
- Should have every year
- We should have one week seminar and use a place like ADCOL or in-service college where it is a bit cheaper so we can increase bus fares for our PLWHA friends in NCD.
- Should have in other provinces
- Only positive people should attend
- Do not discriminate against negative PLHIV who have the heart to do the work and be part of PLHIV



Reflections

- I liked listening to PLHIV from outer provinces – how they tackle HIV from their own pockets and their own hard work – I am from Port Moresby. I think we are receiving VIP treatment while others are struggling.
- I like that PLHIV can have a job

Praise

- 100% fine
- Excellent
- I find it amazing to see people like myself stand up and talk with such confidence
- It was good to see what Poro Sapot is doing for men who have sex with men
- Ken from NAPWA - it was very touching
- 22 yrs positive and partner negative – Inspiring
- The conference is the best
- Advocacy – powerful and useful process
- I give credit to AusAID through I gat Hope that made this conference a successful story. Together we can make a difference.
- It runs well and is well organised; thank you organising members
- It was really good because everybody took part and learned something from each other
- I really love this network because it's very useful to me
- I learnt many useful things and I want to know more
- I don't know what to say, it's very good. I hope for a bigger and better one next time. Thank you very much.
- I love and thank you



Attachment 1 – Program

Sunday 02nd November 2008

10.00am - 2.00pm	Registration for members of Igat Hope Port Moresby Registration for invited partners and observers	Secretariat staff Florence Momo Rei Frank
2.00pm – 5.00pm	Opening of the conference (Separate Attachment)	Don Liriope Annie McPherson John Rule – NAPWA

Monday 03rd November 2008

08.00-0830	Registration (for Port Moresby members and invited partners ONLY)	Secretariat Staff
0830 – 10.00	Plenary Session: “Access to Treatment, Care and Support” Presenter: World Health Organisation Department of Health NAPWA—John Rule President of Igat Hope - Miss Helen Samilo 3 Representatives from other provinces: — Tru Warriors / Kiunga & Igat Hope Milne Bay	
10.15 – 12.00	Discussions on the morning session presentations Actions & Way forward	
12.00-1.00	LUNCH BREAK	
1.00-3.00	Session 1: Surveillance Session 2: Research	Dr. Kitur - Health Dept Angela Kelly Mr. Murray Couch Jeffery Grierson
3.00-3.15	AFTERNOON TEA BREAK	



3.15-5.00	Session 1: Skill Building Knowledge Management—Advocacy	Lydia Martinez
	Session 2: Skills Building Activity Grants Session 3: VCT and Treatment	Ruth Wainetti -NACS Dr. Gideon – Heduru Clinic

Tuesday 04th November 2008

8.00-8.30	Registration of Port Moresby Members Registration for invited observers
8.30-10.00	Plenary Session: Positive Prevention Presenters: National AIDS Council Family Health International NAPWA—Susan Paxton - John Trigg Poro Sapot— Toper
10.00-10.15	MORNING TEA BREAK
10.15-12.00	Group Discussions on the plenary session. (Actions & Way forward) Positive Women Positive Men
12.00-1.00	LUNCH BREAK
1.00-3.00	Session 1: Reproductive Health Presenters: Marie Stopes Session 2: Home Base care Presenters: Family Health International
3.00-3.15	AFTERNOON TEA BREAK



3.15-5.00	Skills Building Session 2: GIPA Presenter: Maura Elaripe & Momoru Morea Session 2: Gender Policy Presenter: NACS Gender Desk /AUSAID
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Wednesday 05th November 2008

8.00-8.30	Registration (for Port Moresby members and invited partners ONLY)	
8.30-10.00	Plenary Session LEADERSHIP,PARTNERSHIP & COORDINATION Introduction Political Leadership PLHIV Partnerships and National Organisations Coordination principles Governance & Leadership 3(1s) Principle	President Igat Hope Dame Carol Kidu NAPWA PASCO PNG Democratic Governance National AIDS Council Secretariat
10.00-10.15	MORNING TEA BREAK	
10.15-12.00	Small Group Discussions	
12.00-1.00	LUNCH BREAK	
1.00-3.00	Presentations and proposals from group discussions	
3.00-3.15	AFTERNOON TEA BREAK	
3.00-5.00	Actions ,agreements and recommendations	Facilitators: Tim Leach Susan Paxton John Rule



Thursday 06th November 2008

09.00- 11.30	Igat Hope Annual General Meeting	Facilitators: -Tim Leach - John Rule
12.30	Lunch	Anglicare StopAIDS
FINISH		



Attachment 2 – Conference Recommendations

Recommendation 1: We recommend that Igat Hope has a bigger say in deciding what HIV trainings are provided in PNG and where they are provided.

Recommendation 2: We recommend that PLHIV be more involved in the design and implementation of home-based care programs. Future home-based care trainings should train more PLHIV.

Recommendation 3: We recommend that IMR's recent research on PLHIV and ART be widely distributed. Stories from the research should be shared widely, including through radio and theatre.

Recommendation 4: We recommend that there be greater effort to help PLHIV understand and use the HAMP Act. We recommend the NAC work harder to implement the HAMP Act and to make sure village courts are aware of the Act. The Special Parliamentary Commission on HIV should support this work.

Recommendation 5: We recommend that MSM have better access to HIV care and support free from stigma and discrimination. Mainstream services should not discriminate against MSM. Some MSM specialist services may be needed.

Recommendation 6: We recommend media and public campaigns that advocate for treatment, care and support for PLHIV.

Recommendation 7: We recommend that there be consultation between Igat Hope and partners who are providing care and support programs for PLHIV.



Recommendation 8: We recommend treatments be available from all accredited sites, with sustainability maintained. We recommend better access to CD4 count machines across PNG.

Recommendation 9: We recommend National Department of Health and WHO consult extensively with PLHIV, especially with treatment guidelines and treatment roll-out.

Recommendation 10: We recommend that Churches in PNG support PLHIV and the treatment decisions that PLHIV take. We suggest Igat Hope seek a meeting with Church representatives to share the results of the IMR's recent research into PLHIV.

Recommendation 11: We recommend more treatments literacy trainings for PLHIV whether or not they are taking ARVs.

Recommendation 12: We recommend that the NAC includes a PLHIV on its NSP Technical Working Group.

Recommendations from the discussions about a national PLHIV network:

It was agreed that PLHIV organisations and groups at the conference:

- Recognise Igat Hope as PNG's national PLHIV organisation
- Want and expect 1 representative on the Igat Hope Board from each region in PNG
- Call on Igat Hope to coordinate the national PLHIV network
- Call on Igat Hope to recognise regional and provincial PLHIV groups, and to sign agreements (like memoranda of understanding) with these groups
- Want greater participation in major Igat Hope activities, such as organising conferences.

Igat Hope can strengthen other groups around the country in the following ways:



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- By communicating well with other groups
 - Supporting regional and provincial groups to be implementers of PLHIV programs
 - Helping build the capacity of other PLHIV groups in areas such as GIPA and advocacy
 - Supporting groups to develop constitutions
 - Offering technical support
 - Lobbying at a national level on issues affecting PLHIV
 - Helping PLHIV groups to talk to each other.

