

Access to Essential Diabetes Medicines for Children in the Developing World

from awareness to action – from 1,000 to 10,000

Saturday, 25 October 2008

9:00 am – 4:30 pm

Suffolk/Sussex Suites, Radisson Edwardian Hotel, London Heathrow

Pledges

Insulin

- **Bioton SA** will donate sufficient insulin to support 1000 children a year starting 2009.
- **Eli Lilly** have pledged to donate enough insulin to cover 4,500 by end 2009; 10,000 by end 2010; and 18,000 by end 2011.
- **Insulin for Life** will take over the insulin needs for the children after age 25 where necessary.
- **ISPAD** pledged structural support and assistance in the training of paediatricians and healthcare professionals in childhood and adolescent diabetes through its membership network.
- **Novo Nordisk** will create a phased programme to provide comprehensive care for 10,000 children by 2015 (this will be run by the company and the World Diabetes Foundation).

Syringes:

- **World Industries** will provide one (1) million syringes initially, and more if needed.

Assurances have been received that further pledges in support of the children will soon be forthcoming. A number of companies are interested in providing support but have to enter into further internal talks before they can pledge their commitment.

Results from the syndicate discussions on identified needs:

Supplies - Collecting Donated Diabetes Supplies

- Rapporteurs: **Alicia Jenkins** and **Ron Raab**

The existing IFL model has worked well for 24 years and has a current capacity to supply 4000 people, so the suggestion is to simply extend it. In a nutshell, IFL collects unopened, in-date insulin and distributes it to areas of critical need. Currently IFL has five outlets. Growth is the priority.

The main points were:

1. The need to mentor additional Insulin for Life collection centers in the developed countries.
2. The need to overcome regulatory barriers to the donation of product. The regulatory and legal barriers need to be explored and overcome. Refer WHO guidelines.
3. The need to increase access to supplies donated directly by industry. Excess from the companies of insulin and strip approaching 'use by' date should be undertaken in a systematic way. It should be to the advantage of all concerned. At the moment waste is being created and life-saving medication and monitoring tools destroyed. Industry need reliable groups to whom they can donate. The models exist where the Association helps out with the collection and distribution of the soon-to-expire products.
4. The need to overcome transport costs. These remain relatively high. There is a need to work with new partners with expertise in distribution and access to networks to address this, eg., DHL.

Discussion

Richard Laing: WHO have international guidelines on regulation. Finalized in 1999, these lay out clearly what the standards are. However, they do not cover test strips

Jean Claude Mbanya requested more information on the demand and supply aspect of the IFL chain and how it is structured.

Ron Raab explained that IFL provides a demonstration model. It is incontrovertible that the IFL model has demonstrated that it works. It is saving 4000 lives a year. While small, it has great potential. The next step is to grow it. As IFL grows, many issues will arise. Regardless, the programme saves lives and is therefore worth pursuing. IFL are committed to overcoming the barriers.

At present IFL is a flat organization. The aim is to establish an IFL in each country.

IFL's five locations run autonomously. IFL global sets the guidelines but the programmes are run locally. John Gattorna gave the example of Lee and Fung (a Chinese company that is expanding through the concept of replicating clusters of management).

IFL expressed a wish to all present at the meeting: Help identify the people interested in the IFL model. The organization will work with these people and train them.

Martin Silink informed the meeting that IDF has two Memoranda of Understanding with IFL: one covering disaster situations and one for the intersection with the Life for a Child Program. The partnership is working extraordinarily well and many strengths in the IFL system have been demonstrated. The model has proven itself as one worthy of support and further expansion.

One suggestion from the floor was to make sure that the relationship between IDF and IFL be a two-way process whereby the Associations are informed of the back-up that is available where shortfalls exist and help is provided to expand the philanthropy.

Corporate Social Responsibility Programmes

- Rapporteurs: **Jean Claude Mbanya** and **Edwin Gale**

The problem can be explained simply as follows: kids need insulin and other supplies to survive. In the West everything that is required is available. We simply need to bring all components together. However, the associated issues are complex.

1. Secure the supply

The first issue is to secure an ongoing supply of donated insulin, strips, syringes and other required products.

2. The difference with monitoring

The need for delivery systems and strips is a complex issue and politically different from insulin. Indeed, strips can cost more than insulin! There are alternatives – urine strips work. Yet it can seem paternalistic to tell countries they cannot have the latest technologies. Companies which work in these areas will have to go back to their Boards to investigate further.

3. A tricky issue of coordination

How do we coordinate it all? Both NGOs and corporations want to help. However, everyone needs a consistent profile in order to sell the project internally. They need to answer the question "what's in it for us?" How can each company deliver the most benefit to the coalition without participating in a 'beauty contest'? How do you retain ownership but still work together? This is a big challenge. Who do we run the programme through? This has to be faced and clear leadership must emerge.

From the industry point of view they need to know what is happening to their donation. Feeling comfortable with the project and confidence that the right process is in place is a crucial pre-

requisite for industry. All the corporate partners are concerned about how things would work on the ground and are willing to help.

A feeling emerged that the need we serve is so powerful that the barriers can be overcome and responsibility, as well as the subsequent glory, distributed equitably among all partners.

Discussion

A company called **Betacheck** works to provide cheap strips that do not require battery-operated monitors, works with CLAN. The company had been invited to the meeting but did not respond.

Anne Marie Felton asked whether the group had reached a conclusion as to who should coordinate the programme. The answer was that the group had not reached a conclusion. The importance of transparency was reiterated. The consolidated response will need careful thought about the ideal structure.

Jean Claude Mbanya indicated that the industry partners joining the coalition all recognized the transparency of the Life for a Child Program. From the start, Life for a Child is seen as a dependable agent of delivery.

Herb Riband made the point that the diabetes environment needs to be integrated. A holistic approach will be required to make the programme work.

Accessibility - Supply Chain – Lessons from AIDS etc.

- Rapporteurs: **David Beran, John Yudkin** and **Kaushik Ramaiya**

Having pilot projects like HIV/AIDS programmes would be useful. Showing that AIDS could be treated was crucial to getting further support. We must illustrate the need for diabetes care and that it can be managed.

Differential pricing such as the programmes offered by Novo Nordisk and Lilly are highly advantageous, yet the information has not filtered to the people on the ground who need to use it. The group discussed how to improve this situation. A suggestion was to talk to the NCD officer who will use the insulin, rather than to the people responsible for procurement.

A suggestion is to involve civil society more heavily during the planning phase.

Education is important because each child with diabetes is different. The child, family and healthcare professionals need education to manage the diabetes.

Sustainability is vital. This makes the Minister of Health a key stakeholder. They often procure drugs and can make money available for diabetes. If they can improve their supply chain, it would be the best long-term solution.

If there is a system for pre-qualification of insulin generics, it may be possible to bring prices down. Insulin pre-qualification is difficult because there is no system currently in place. An ideal step would be to put a system in place and develop new generics.

Procurement in AIDS is undertaken by the global fund. In diabetes, it would be the government. Another difference is that there is no single diagnostic indicator.

Vertical vs. horizontal programmes – AIDs money is not allowed to be shared with other diseases (people with AIDS and diabetes would not get help for their diabetes). We would need to tackle the duplication and/or lack of coordination.

Diabetes Education Needs

- Rapporteurs: **Marg McGill** and **Sheridan Waldron**

Education programmes should be child centric. In the short-term it is all about keeping the child well. Long-term aims would be to achieve the normal milestones of childhood.

Education will need to be culturally sensitive and integrated into the community.

The model would be an assessment plan, a needs analysis, implementation and then evaluation.

For assessment the questions would ask: how do children learn? What are the needs? What teaching tools exist? What tools do other diseases use successfully? Can models be mirrored?

Partnerships with organizations with a paediatric focus (ISPAD, CLAN, Save the Child, MSF) would be key.

Work with diabetes associations (initially the education component would be volunteer led).

Develop a curriculum with a paediatric focus for healthcare professionals.

Programmes would need to be developed for children, parents and carers.

Awful teaching tools exist (e.g. Healthy Pyramid giving a negative connotation to staples such as rice). Simple teaching tools would need to be created/copied. The biggest issue is food.

Generic programmes would need to be tailored for each country.

It will be necessary to empower healthcare professionals, professional organizations that may or may not be integrated into the local diabetes association.

It will also be necessary to empower people, particularly laypeople in their own groups.

Lilly will support development of conversation maps for Africa.

It will be important to evaluate what is useful.

It was suggested to add education questions in data collection sets to get educational outcomes.

Discussion

For diagnostics it is important that education and tools are married. You can supply strips. It does not matter, however, how many times a child's blood glucose is measured if no action is then taken to alter the insulin regime. Education will help people to learn the tool so that it is more than a one-off.

Harmonizing NGO and Government Efforts

- Rapporteurs: **Ann Keeling** and **Jonathan Brown**

The importance of good communications between NGOs and governments was stressed. It is a lot of work and it takes many forms:

Lobbying; identifying people who have diabetes in government; undertaking work for the government (clinics, courses, distribution); organizing meetings around topics to educate the government and get things started; working on forums to get ministers and different groups together to talk. NGOs could recruit from the ranks of government.

It is critical that governments have a plan – NDPs, chronic disease programmes, etc. It creates a framework in which NGOs and companies can work. It encourages donations and increases coordination.

Key point from Tanzanian experience – the importance of getting data to government officials, especially when they are not paying attention to the problem. – Health Action (WHO), Barometer (NN), along with the IDF and IFL studies will all help.

We need to push NCDs. We share a lot of common interests and solutions. If a government has a plan for chronic diseases, things work better.

Suggestions for NGO sector would include an increased focus on the large donor agencies (Gates, World Bank, etc.). There is a huge opportunity to make the case on the back of growing diabetes awareness. Expand the twinning initiatives – they have already proven quite successful.

Discussion

Azad Khan explained how political party affiliation may be counter-productive. Bangladesh is successful because it is able to remain apolitical

John Yudkin was interested in the idea of looking for support for type 1 diabetes from a large foundation. He suggested that arguing for 10,000 children with diabetes will not persuade the big foundations. We need to realize that the wider community arguments will be more useful. Horizontal integration of the message is needed.

Owen Robinson from the Clinton Foundation, present as an observer, suggested that if the group can translate the arguments presented into data, it would create a much stronger case to go to the foundations, and other large donors.

Anne Marie Felton explained that IDF Europe and FEND had undertaken an EU audit (27 countries) – and looked at which countries had or did not have NDPs. Experience shows that the situation improves if you measure and compare situations across borders. Governments are encouraging to perform better after each audit. On an IDF Regional basis, a map of the state or presence of NDPs should be drawn up.

Harry Keen made the point that it is important to build sustainability in the relationship between NGOs and governments. This is not a one-off. That need for continuous input and the required resources must be recognized.

It is a push-pull situation – reaching out to the developing world, the developed world needs to be involved and know the issues. Public health problems beyond national borders are largely unknown, especially in the US. There is a need for both worlds to help each other out.

Comments were made on NCD strategy and the role of individual associations. People with various chronic diseases need support. All the interest groups need to align to achieve greater success.

The question was asked as to whether the WHO was looking at chronic diseases of childhood? Richard Laing explained that asthma is currently a hot topic and expensive to treat. Asthma and type 1 diabetes can develop complementary strategies. When we make a push towards government alignment would be possible. Both start in childhood.

The comment was made that the Gates Foundation is focusing on childhood. The International Union against TB and Lung Disease is now undertaking the procurement of inhalers at much cheaper price.

Societal Role

- Rapporteurs: **Larry Deeb** and **Wayne Edwards**

IDF has pushed for twinning efforts. A successful example is the Diabetes UK and Mozambique experience. A recommended lesson learned was to invite the MoH from developing countries to an event.

IDF twinning programmes are now in 18 countries. Also get funding through Rotary. Rotary can work with WHO to identify receptive MoH in these countries.

Society has a responsibility to bring these children to adulthood as productive citizens. Rotary donates money to pay for learning/trade programmes in developing countries. When they age out of this program, they can live productively and have a job.

Monitoring the Support for 10,000 Children

- Rapporteurs: **Graham Ogle** and **Ann Albright**

Monitoring and Evaluation – it is impossible to do much in the Life for a Child Program (L4AC) without monitoring and evaluation. Form for Life for a Child was the starting point.

A local Independent auditor is required - someone who monitors the supplies and if they are being used properly.

The database and data collection tool for the system should be as simple as possible but it must be noted that collection is necessary.

There is a need for basic core elements that these forms collect. This then has to be shared with a database. L4AC working to achieve this.



There is a need to collect and monitor results, but also a need to unify results for everyone's use.

Education should be added to the form – people with diabetes need to be able to use the information.

Main monitoring issues are:

Monitoring of the patient (HbA1c machines, - get machines in more locations).

Financial– financial cases for continuing services.

Discussion

Richard Laing from WHO stressed that evaluation is very important. He thought that it was important to try to find control groups and encourage the use of qualitative evidence (e.g. Binod's story). For example, follow the same family in the beginning and end with pictures to paint the picture of impact. He appealed for cases studies to put a face on the problem. The message is clear: If it is long and boring, no one will read it!

Jean Claude Mbanya stressed the need for monitoring within countries to make sure that everyone gets the insulin. This will have to include access in rural areas. Local audits will be required.

Administering the Support for 10,000 Children

- Rapporteurs: **Liz Peers** and **Rhys Williams**

The main issues emerging from the discussion were:

- The operationalization and organization of supply, distribution, education and care.
- The need for national diabetes plans with an identified supply chain.
- The need for a coordinated global alliance. The question to raise is who should coordinate this?
- The management of any alliance so that everyone gets their say.
- On a national level, government support is vital. It depends on the national situation as to how easy this is to secure.
- National associations are major players. Some have infrastructure and knowledge of the country. Other countries may need support to set this up.
- The need for local champions and a need to vet these local champions to ensure that they can provide the care at the level required.

It should be possible to choose between existing distribution systems. Many organizations in the room have existing infrastructure in the countries for distribution.



Distribution systems come in two kinds – distribution through health or others (education, courier services, faith organizations).

The key to administration is through local centres. Distributing insulin to the homes of children is not ideal. Children need health centres for monitoring. If families need to travel to centres, they need the system to compensate them for travel costs. A way to maintain contact between the children and the centres is required. Most countries have efficient mobile phone systems even for the poor. Perhaps this could provide a solution.

Sustainability – the administrative solutions need to loop back to the Unite for Diabetes alliance. Data collection about the effects of the programme need to flow so that donors know where to put funding and support activities.

Next Steps

John Gattorna

- Pilot programmes – we should set a date by which the above mentioned initiatives should happen and provide a timetable. If we wait too long, this coalition meeting will just have been a talking shop.
- Commitments from the organizations – some currently received and acknowledged; other parties to revert back after the event. 18 countries are working so far. We require an analysis of what has worked and what has not. We should look at those in context, and target the next 18 countries. What can we do to reach the 2009 targets?
- Lessons learned – we need a quick report. We have all the required information. See what needs to be enhanced and/or changed.
- We need to know the extent of the problem – we need an inventory of the other countries where we do not have data. Find the children with diabetes and the people that work with these children locally.

Paul Madden –suggested that everyone in the room go to someone in the non-diabetes world who can assist us in the next two weeks. While stressing his awareness of the ethical issues, Madden emphasized the need to find new partners for this initiative. Pepsico has a magnetic marketing reach which gets places J&J cannot. If we are truly going to make this go rapidly, we need to think about who else we can invite to the table.

Jean Claude Mbanya – reminded the meeting that from the outset we had wanted to form a coalition to move forward. We now need to sit down and write up a proper business plan. Within the next month or two we should get a global perspective on what we want to do, how to do it, the finance required and the timeframe. The issue is global, not just Africa. We must move the process forward with timelines. Everyone of us needs documents to show to our respective Boards.

Who will write the Business Plan? Suggestions were Graham Ogle, HOPE worldwide, IDF and John Gattorna.

Phil Riley explained that materials would be available for the following two weeks from <http://www.idf.org/london> (available until end of World Diabetes Day).

Richard Laing from WHO advised drawing on the experiences of other public health practitioners. MSF has a huge network and should approve.

Larry Deeb explained that he had met with MSF immediately prior to the meeting. They do not know how much they are doing with diabetes and are not doing quite as well as they would like. They will do the best they can. At present they do not think diabetes is that big of a problem. They are willing to learn more.



Martin Silink stressed that people have recognized the groups we have brought together. Solutions will be multi-sectoral. We now have a practical problem to solve. He cited the UNR as an example. This will only work under our Unite for Diabetes banner. People must have ownership, coming under that umbrella.

A business plan is necessary but we must hurry slowly. The plan has to be right. We have got a system working now (L4AC) so we have a firm foundation on which to build. We now have to be pragmatic. Large number of partners need to come under this Unite for Diabetes alliance (supply-chain, etc.). This is now beyond the diabetes arena (Rotary and other groups have to be involved). Various associations have to be involved.

We will need an incredibly wide consultation process. The plan has to be global, not just focused on sub-Saharan Africa. Horrific conditions exist throughout the world.

We need to make sure there are big coalitions involved (other medical groups).

John Gattorna explained that we need to put all the pieces together. Those present are the orchestrators of this new movement to reach all these children.

Martin Silink added that the issue is more than insulin and monitoring. We need the companies dealing with lipids, and all the complications of diabetes. This is not just an IDF initiative. He reiterated the need to come together under the Unite for Diabetes umbrella. He expressed his gratitude for the involvement of WHO and emphasized that outcomes need to be in the format that WHO can use.

Closing statement

Martin Silink

It had been an incredible day: "October 25 in London, 2008 will go down history as an event that will be marked in the diabetes world as having changed the direction."

The summit had drawn together influential thought leaders, agents of change.

"We now have the imperative and the commitments to move forward."

The meeting has moved us from the theoretical to a pragmatic framework.

We need to get feedback from guests and find out what support is there. We need to work out a system of leadership so that everyone is represented.

A message of gratitude was given to:

- Diabetes UK and its Board for an important signal of support.
- World Industries for the support of the reception and the generous donation of syringes.
- Novo Nordisk and Lilly for their support and generous donations.
- Bioton SA – who were also welcomed to IDF and to the alliance, and thanked for their pledged donation.
- All participants for making it a historic day.
- IDF staff for the tremendous effort behind the scenes.

In his final words, Martin drew attention back to the World Diabetes Day theme of Diabetes in Children and Adolescents. He explained the opportunity to light the UN in blue to mark the day and the opportunity in New York to tell the UN and Rotary of the outcomes of what had been a truly wonderful meeting. He acknowledged that the development of this coalition is the best way for this World Diabetes Day theme to be recognized.

John Gattorna added his thanks and closed the meeting.
