Annual Report

2012

Summary Update

This report is an update on HDI's activities in 2012 and through April of 2013. The lives of more than 240 women and more than 1,030 babies have probably been saved so far, and WHO predictions lead us to think that between 56 and 112 women would have gotten obstetric fistula, were it not for HDI's obstetric fistula prevention program.

In October 2012 I said, "The six-seven months since the Board's meeting in San Diego have been among the most exciting for a long time! " In fact, the six months since then have been even more exciting. And potentially momentous!

Niger decides to resolutely prevent women bleeding to death at childbirth

As described in more detail below, Dr. Zeidou, HDI's Resident Representative in Niger, and I visited Rome last October to present Niger's successful obstetric fistula prevention results. We came across news about preventing and treating post partum bleeding. Almost everywhere, bleeding is the reason women most commonly die at childbirth. The scientific community had developed, and WHO-endorsed, new approaches presented at the conference of the International Federation of OB/GYNs.

HDI introduced Government of Niger to these findings in late February 2013, and the Minister of Health decided to implement prevention as well as all three new treatment approaches, nation-wide, aiming to begin in the summer of 2013

Togo is again treating 3.3 million for Neglected Tropical Diseases (NTDs)

In early May, Togo is again treating about 3.3 million people, especially women and children, with three drugs, in five combinations depending on local disease burden. NTD efforts in Togo are funded by a USAID sub-grant to HDI.

A Transmission Assessment Survey in 2012 confirmed again that Togo is the first country in Sub-Saharan Africa to rid itself of LF (lymphatic filariasis) transmission. HDI helped from the start in 1997 to the end. Also in 2012, a detailed survey confirmed trachoma to be so rare in Togo that Mass Drug Administration against it is not appropriate. River blindness (onchocerciasis), schistosomiasis, and intestinal worms that hamper intellectual growth and other developments, are Togo's targeted Neglected Tropical Diseases.

Guinea Worm Eradication; almost there, and HDI Rewards still being offered

Funded by Geneva-based Fondation Pro Victimis, HDI's Guinea Worm Rewards still help people find the last remaining cases and "prove" cases no longer exist in previously endemic areas. 2013 may see fewer than 100 cases in the four countries that remain endemic. In 2012, all but 21 of the world's 542 cases were in South Sudan, which then achieved 90% reduction to 6 cases in 1st quarter of 2013. Perhaps even South Sudan will use rewards in 2014.

Anders R. Seim, MD, MPH

Executive Director

1. Initiative to Prevent and Treat Post Partum Hemorrhage

In mid-February 2013, Prof André Lalonde from Canada kindly brought key findings from FIGO's October 2012 Conference in Rome, to Niger. FIGO is the International Federation of OB/GYNs. Prof. Lalonde is a global leader and its former president.

Hosted by Niger's Minister of Health and under patronage of Niger's First Lady, Dr. Malika Issoufou, a two-day Technical Meeting was held first. Participants came from different regions and districts, the ministries of finance, planning, and health, UN agencies, and international NGOs. The Technical Meeting was followed by two days of Policy Discussions with key Ministry of Health decision-makers and their closest advisors. By the time Professor Lalonde headed back to Canada, a broad Ministry of Health planning committee was developing a Policy and Implementation Plan for Niger's Initiative to save over 1,200 women's lives each year by preventing bleeding-deaths at childbirth, and prevent 47,000 cases of incapacitating anemia.

On March 18th, the Minister accepted his staff's report, approved the Plan, and chose July 1 as the starting date. Niger's Ministry of Health and HDI have been working hard to put the funding and technical pieces in place, right from the moment the Minister announced in February that he will implement this Initiative. The target start-up date certainly has turned up the heat on getting everything into place!

To our knowledge, Niger's Initiative to stop women bleeding to death at childbirth makes it the first country to move resolutely forward based on the research findings presented in Rome and endorsed by WHO. At the conference, each components was documented as being effective. Yet, Niger will be the first country to use them all in combination, nation-wide, to rapidly save women's lives.

Niger decided to roll out its Initiative to Prevent and Treat Post Partum Hemorrhage much more intensively than we thought it likely they would. Having decided there is no way to deny women in any part of the country the benefit of this approach while others are being saved, they chose simultaneous roll-out nation-wide. The Ministry will run this as a fully integrated cross-departmental initiative under the responsibility of a small steering group. Also, the Ministry's top leadership plans to have the Initiative as a regular agenda item at its bi-weekly meeting.

How are Women's Lives to be Saved?

A Prevention Dose of tablets is to be given to each woman to take home from her final, 3rd Trimester prenatal consultation, with clear instructions to take them as soon as the baby is out and one has palpated her tummy to be sure there is not another baby inside. This medication can prevent excessive bleeding after birth in about 97% of cases, and studies in three countries on two continents have shown that women use it correctly in the overwhelming majority of cases, also after home-births. Niger's leadership wants to protect even those women who give birth in villages, either by choice or because the birth started earlier than expected, in women who were planning to give birth at a health center.

Manifest bleeding after births (more than 500 ml. or a soaked traditional cloth that every woman has with her, called a pagne (pronounced "panye")), will be treated in health settings, initially using the same medication, which is successful within 20 minutes in a majority of cases.

Niger's "Prevention plus 3-Step Treatment" against post partum bleeding consists of:

Prevention 1st, using the Niger program's misoprostol dose. Niger chose a slightly lower dose than others for several reasons. The Niger dose gives fewer side effects, yet studies indicate it is as effective as the higher, now recommended prevention dose. And WHO writes there is no evidence to suggest the higher dose is more effective. Also, a high prevention-dose cannot be combined with WHO's recommended treatment without overdosing the patient.

3-Step Treatment if the woman bleeds more than one soaked pagne cloth (about 500 ml):

> **Step 1: A treatment dose of misoprostol.** This is in the hands of health workers in hospitals, Health Centers, and "Health Huts" that have a nurse or a midwife.
>
> **Step 2: A condom tamponade + antibiotic.** Insert a condom tamponade, filling it with warm water using a 50 ml syringe. If bleeding stops, leave in place 6 hrs and then start removing water, 25 ml every 15 minutes.
>
> **Step 3: Non-inflatable anti-shock garment, and get her to surgery.** If she bleeds after 6-12 minutes in spite of tamponade, put on the anti-shock garment and get her to a place that can do definitive, life-saving surgery.
>
> Step 3 is to be started if Step 2 did not stop the bleeding, or if the woman is already in shock or pre-shock when she arrives at a health center or hospital.
>
> If a woman arrives in shock or bleeds profusely, all three Steps shall be implemented at once, immediately, and she shall be sent by ambulance to a hospital where definitive surgery can be done. Every patient who has been in shock should be brought to a hospital that can do such surgery, where blood can be given and other things done to get her safely out of shock, even when the anti-shock garment works, because shock can be life-threatening even if bleeding has stopped.

Implications for HDI

HDI took on the challenge of bleeding deaths at childbirth because one cannot stand idly by as women die needlessly every day, when one has stumbled upon an opportunity to combine simple, low-cost interventions that even a country like Niger should be able to implement, to save thousands of women's lives. Although bleeding is the main cause of maternal birth-related deaths in HDI's current project

areas, now that blocked childbirth is gone and other causes have been brought more under control, this really is something we "picked up from the side of the road", where the ethics of the situation simply demanded that we at least try.

So, now what? In my view, for this Initiative to work sustainably on a truly large scale, "the big boys and girls" must take it on. HDI can help get it going. But it seems completely unrealistic for us to be the main ongoing source of assistance for this initiative without solid, major external support, such as multi-year funding from USAID, which I imagine to be completely unrealistic, though it shouldn't be!

What we have done so far is to try all the avenues imaginable. An email in February to current and former contacts resulted in some donations; we are working with potential larger donors including UNFPA; and we will try to mobilize via the internet for Tamponade Kits that will cost on the order of $4.32 each to put together.

UNFPA-Niamey indicated they might buy some misprostol and help with the critically important Baseline Survey, and we have followed up, also with UNFPA-Geneva. A sampling technique protocol for the Survey has been drafted by HDI's medical epidemiologist, Dr. Rachel Bronzan, thanks to generous support provided by the Seth Sprague Foundation.

Also, Norway's Ministry of Foreign Affairs (MFA) has recently shown interest in Niger. On April 17, they indicated potential willingness to fund the Baseline Survey via HDI-Norway and misoprostol procurement via UNFPA. It appears they may be willing to support misoprostol procurement for three years, and a refined proposal has been sent in accordance with feed-back provided by them in late April.

We also established a Twitter account in February - www.twitter.com/savingwomenHDI.

Monthly data collection from 3,200 locations throughout Niger via mobile phones will also be important. Having researched solutions for this from the US and struggled mightily with a solution that sounded good at the outset, we stumbled across the free, open-source DHIS2 (District Health Information System2) being implemented in more than 30 countries in Africa and Asia. And Niger turns out to be one of them. Anders visited Burkina Faso's Ministry of Health while there for a Guinea Worm Program Managers Meeting in April. That and a follow-up meeting with the developers indicate this is probably exactly what we need.

In this situation, HDI should start a broad-based twitter and perhaps facebook campaign to raise funds for components of the Tamponade Kit costing about $4.32, and the anti-shock garment. Those can be used 50-100 times and cost $65 each when procured straight from the factory. We aim to "ask the world" for multiples of $4.32 for the 11,540 Tamponade Kits that need to be pre-positioned, ready to use, and multiples of $65 for the 3,560 anti-shock garments needed.

If Gvt of Norway decides not to procure all of the needed misoprostol, we can send an additional appeal for multiples of "56 cents to save a woman's life".

Documenting its impact is a key component of this Initiative. That should take much less time for bleeding-deaths than for obstetric fistula; about 1 year ought to do it.

If this works as intended, it ought to be a model for essentially all developing countries to follow, in which case it would be something for large bi- and multi-lateral donors and developing-country governments to implement.

2. Obstetric Fistula Prevention in Niger and expansion to other countries

More than 240 women and 1,030 babies have probably been saved so far, and WHO predictions lead us to think that between 56 and 112 women would have gotten obstetric fistula, were it not for this program.

4-Year Results in Niger are strong

"Year 4" data for Niger's Bankilare area show birth-related maternal mortality numbers improved even more, now to Guatemala's overall maternal mortality rate!

When expansion-areas where work began in 2010 are included, **56,742 consecutive births have occurred without a single death from blocked-childbirth** through March**.** The most recent obstructed labor death was in May 2008. Remember, this was reportedly the main reason women died at childbirth in the Bankilare area before the project, as in remote parts of Afghanistan.

The proportion of babies born dead or dying within three days also continued to fall. Most encouraging is that the rate of decline flattened out, additional evidence that the numbers are real.

From "Year 1" (July 2008 to June 2009) to "Year 3", "Baby Deaths" declined 61.5%, from 3.5% of all births to 1.3%, where babies were "born dead or died within three days". To Year 4, the change from Year 1 was 64.8%, to 1.2% of births.

This means we reduced "Baby Deaths" by almost 2/3 through interventions aimed solely at securing maternal survival! Further reduction will probably require baby-specific intervention. A successful set of simple interventions to help babies survive their first hour of life is the "Helping Babies Breath" approach, for which materials recently became available in French. UNICEF is supporting introduction of this approach in Niger, and we aim to have it introduced by them in the ongoing fistula prevention project areas at the earliest opportunity.

Expanding obstetric fistula prevention in Niger

The aim has all along been, and remains, to expand HDI's obstetric fistula prevention program "as rapidly as results justify". It turns out that rapid prevention of obstetric

fistula works! Women's lives are being saved and fistulas prevented. The program has expanded from a population of 100,000 to cover more than 263,000 people, now across areas the size of Rhode Island and Delaware combined. And it still works!

In July 2012, a different group started doing obstetric fistula prevention using "the HDI-approach" as part of what they do at a new obstetric fistula treatment hospital in central Niger, some 500-600 miles east of where we work. HDI helped them through the planning and budgeting phase concerning obstetric fistula prevention. We helped establish close working relationships with local health authorities, provided the robust cotton "flip chart" that is placed in each village in the hands of the two village volunteers (a woman and a man in each community), and we supplied the village-data registration booklets with self-copying paper so data can be collected monthly while the community retains a copy of its own data. Etc.

HDI intends to continue this close collaboration, to assist that group as best we can, also with data analysis as they come up to completing their first full year of obstetric fistula prevention.

In 2012, UNFPA (The UN's Population Fund) expressed interest in supporting expansion of obstetric fistula prevention to yet another part of Niger. HDI has therefore worked with them and the national health authorities in budgeting and planning with the aim of starting work there too in 2013. So far, however, there is no indication that UNFPA's hope of securing funding this year has come to fruition.

Of course HDI remains positive to collaborating with "all comers" in Niger, to expand successful obstetric fistula prevention to all parts of Niger as rapidly as possible.

Expanding obstetric fistula prevention to other countries

For the past 2-3 years we have also explored the extent to which other countries might be interested in implementing Niger's obstetric fistula prevention program in an effort to replicate its good results. Ethiopia was one possibility. A hoped for introduction to Ethiopia's Minster of Health did not happen, and one continues to look at opportunities more broadly. We have identified five countries in East Africa where the policy situation is conducive (free obstetric care including c-section when needed in obstetric emergencies), maternal mortality is high, and obstetric fistula is a problem. We are currently collaborating with others, also in the corporate sector, to see whether political leaders in one of these countries might be interested.

Expanding the "Midwife-Assistants" initiative in Niger

With Pro Victimis Foundation support, the second set of "midwife-assistants" completed their theoretical and practical training at Niamey's midwifery school and graduated on January 3rd this year. That is very exciting! The first group graduated in the summer of 2011, and they have been doing very well since then.

With these women too back home and working since their graduation, one in each community where a health center exists, the intervention proposed by Dr. Zeidou is bringing this important resource to Tera District's entire 596,000 population.

The midwife-assistants intervention successfully addresses the problem that health center nurses are almost always men because driving a heavy all-terrain motorcycle is necessary to do a nurse's job in these areas. Also, the nurse is often away on vaccination campaigns, for meetings in the district capital or other reasons. So, sometimes no health worker is there to help women who show up in labor, except where we have a "midwife-assistant". Now, a woman trained in prenatal care and obstetrics is available in every health center across this district, Niger's 2nd largest!

3. Neglected Tropical Diseases (NTDs) in Togo

USAID continues to support "Integrated Control of Neglected Tropical Diseases" in Togo through HDI.

The 2013 annual round of Mass Drug Administration (MDA) started the week of April 29. It aimed to reach about 3.3 million people nation-wide, using five different combinations of three drugs, with the exact combination in each locality depending on the local prevalence of each disease. About 6.5 million doses of medication were distributed to the Togolese population.

An independent coverage survey was conducted in 2012, because integrated MDA campaigns are logistically complex and reported coverage may not reflect the actual coverage attained. HDI's part-time medical epidemiologist, Dr. Rachel Bronzan is a veteran of CDC's Epidemic Intelligence Service (EIS). She designed this novel study, since no clear guidelines exist for sampling in such a complex distribution scheme. Attained coverage surpassed WHO targets, and the information we obtained was used to adjust supervision during the 2013 MDA, to provide close follow-up to districts where there appear to have been problems during 2012. Dr. Bronzan's work on the Togo project is paid for by USAID (the US government).

USAID is genuinely pleased with the work HDI and Togo are doing under their grant; they decided to extend the grant for an additional two years without a new round of competitive bidding.

4. HDI-Rewards in Guinea Worm Eradication

HDI continues to offer cash rewards to help find the last few cases of guinea worm disease in countries where few cases remain, and to help prove it no longer exists in formerly endemic countries, as we have been doing since 1993.

In Chad, HDI funds are sent through Carter Center, which has an office there. In Niger, funds for confirmed imported cases from Mali are disbursed from HDI's own office in Niamey. In Mali itself, funds remaining from a transfer some years ago have now been depleted, and collaboration with Carter Center will be sought for disbursement there too. In Ethiopia, rewards were paid by HDI for years, but have most recently been covered by Carter Center. South Sudan has achieved a 90%

reduction in cases for the first quarter of 2013, to 6 cases, compared with 61 cases during the first three months of 2012. At this rate, South Sudan too may be ready to introduce cash rewards, at least in parts of the country, beginning in 2014.

5. Finances and Administrative Arrangements

While this is of course as it should be and always has been, HDI again received a clean audit, this time for the year ending June 30th 2012.

Tom Johansen of the HDI-Norway board, an MBA and former chief financial officer of the Radisson hotels chain, kindly continues to also provide financial oversight assistance to HDI Inc on a pro bono basis. Liv Seim, Anders' wife, continues to do bookkeeping for HDI Inc too, also on a pro bono basis.

With our current arrangements, it is possible to be literally up to date. Liv normally posts disbursements in the accounts the same day they are paid. A paid accounting firm checks entries for any mistakes.

6. Funding Developments

The Seth Sprague Educational and Charitable Foundation continues to support HDI, among other things so our part time medical epidemiologist, Dr. Bronzan, can support Niger's childbirth-related work. Sprague Foundation grants must be used on US-based activities, and have been critically important to HDI's success, funding our "Fistula at the Carter Center" meeting, website renewal, and all manner of essential activity in the US for which funding is often very difficult to secure.

In October 2012, the **Izumi Foundation** generously decided to provide a new two-year grant for obstetric fistula prevention in Niger.

7. HDI's Website

HDI continues to receive spontaneous, complementary feedback on our website, renewed with Seth Sprague funds. We are reasonably pleased with the site, not least the way we have managed to prominently yet discretely profile major supporters of HDI's work in a subject-specific manner at the top of each project section.

Even so, "Something need not be bad to have room for improvement!"

A very significant problem with the website is the lack of updating. Further improvements are also needed. For example, the map seen when looking at project-specific information remains in place underneath as one scrolls down, making the text less easy to read. While we unfortunately have nobody who can take care of continual updating of the site, Anders is acutely aware that he has not been as good as he should be about getting technically competent people to change specific

portions of the site as they become out-dated, to develop a new section when HDI expands its program activity to a new area, etc.

Conclusion

HDI's supporters are contributing to important achievements.

Currently, the initiative to rapidly prevent women from bleeding to death at childbirth, nation-wide in Niger, is HDI's most exciting endeavor!

HDI's program to prevent maternal mortality and obstetric fistula continues to deliver impressive and ever-improving results, year after year. Since this approach works for > ¼ million people in some of the world's most inaccessible areas, it ought to work elsewhere too.

We are using USAID-funds effectively to improve the health and socio-economic wellbeing of millions in Togo through Integrated Control of Neglected Tropical Diseases.

And HDI continues to help rid the world of the last 542 cases of guinea worm, the disease for which the organization was founded.

In short, HDI continues to contribute to health and human dignity in meaningful ways, benefitting millions of people.