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## Jonathan Mann Award for Global Health and Human Rights

### Nominator:

Annette Donnelly, Walking With Angels, Inc. President  
1111 W St., NW, #4  
Washington, DC 20009

EEmail: [annette@walkingwithangels.org](mailto:annette@walkingwithangels.org)

Website: <http://www.walkingwithangels.org>

### Why are you recommending this person for the Jonathan Mann Award?

In the twilight of 1948, a war weary world learned that their United Nations had adopted and proclaimed a Universal Declaration of Human Rights, and began to hope. In that same year, Mary Sarah Owens was a nine year old girl, growing up in her beloved Ireland wondering, as all children do, what the future might hold for her? Sixty years later, Sister Mary Owens found herself standing before the United Nations NGO subcommittee on HIV/AIDS, substantively reminding them of universally declared rights protecting all, especially the most vulnerable under Articles 1, 2, 3 and 25. In Kenya this year, two important anniversaries will be celebrated by 3,691 HIV affected children, along with their donors, caretakers, extended family members and the community at large. Although modesty and a matter-of-fact manner tend to keep her out of the limelight, Sister Mary will celebrate 40 years of service in Kenya, in addition to her 71<sup>st</sup> birthday. Her work inspires all of us who love children and wish to see them grow up as fulfilled and healthy members of society, capable of leading the future.

Although earned, Sister Mary will not sit quietly through accolades and celebrations. She uses each opportunity with her children to praise and nurture their unique qualities, like any parent. Eighty six percent of the children that Sister works with are infected with HIV/AIDS; of these, the vast majority are orphans. All have been affected by the pandemic. To Sister Mary, each child is a gift, precious and worth fighting for. The specific battle varies with time, technology and the children themselves but the theme is constant; *all children have a right to a bright future.*

I first met Sister Mary in 2002 and I remain unequivocally convinced that she treats each child as her own. Not, "as if" a child were her own, but AS her own. Sister Mary is the Executive Director of COGRI Nyumbani, the organization she co-founded in 1992 with her dear friend Fr. Angelo D'Agostino, for the care of HIV infected and affected orphans. She brings a unique background to her role of working woman; she is an accredited psychotherapist, a religious, a teacher and former School Principal in addition to co-founding the Centre for Religion and Psychiatry as well as the Children of God Relief Institute. She is also surrogate mom for literally thousands of children whom others have abandoned and forsaken. Upon taking leadership of the organization in 2006, she has made it her quest to equal the standards of care surrounding pediatric HIV/AIDS, relentlessly striving to make routine protocols practiced in developed countries, like drug resistance testing and appropriate drug therapies, available to her 3,138 HIV+ children served in Nyumbani programs.

Health, a many faceted and prized gem, is a birthright elusive to Sister Mary's children, which was denied to them through no fault of their own. Today as I write, 3,691 children are served by Nyumbani Children's Home (an orphanage for HIV/AIDS children), Lea Toto home based outreach care and The Village settlement in rural Kitui. Of these, children, there are 1,662 children currently on ARV therapy. The children living in Nyumbani home pioneered pediatric ARV therapy in Kenya and have long experience with supervised daily adherence, enhanced nutrition, monthly checkups and, at minimum, a bi-annual viral load and CD4 blood test (this exceeds the Kenyan government

recommendation of an annual CD4 for HIV/AIDS patients). Despite this level of care, children have begun to experience failure on currently available drug lines. One child, Sammy, died when a 3<sup>rd</sup> line salvage therapy of available drugs failed. Forty-Nine percent of the children living in Nyumbani Home are on second line ARV therapy and 4% are currently on 3<sup>rd</sup> line, salvage therapy. In Lea Toto, the home based care program serving 3,000 HIV/AIDS children, a recent abstract presented by Dr. Jean Bowyer, pediatrician for Lea Toto, stated that "Drug resistance is the emerging issue of deep concern". First line Lea Toto children on ARV therapy were sampled for viral drug resistance, thanks to the collaborative efforts of Kanazawa University in Japan and CDC, Kenya. To quote the abstract; "of great concern is the finding that 46% and 32% respectively, showed significant resistance to abacavir and didanosine even though they had not been exposed to these drugs".

Sr. Mary is quick to point out that both adherence and inheritance are issues to consider with resistance. She reminds us that the cause of a mutated virus that is drug resistant will hardly matter should it develop and ravage the population. Pediatric HIV/AIDS drug resistance issues are creeping up exponentially in Kenya, per conversations with physicians specializing in pediatric HIV/AIDS around Nairobi at Gertrude Children's Hospital and the University of Nairobi School of Medicine, in 2009. The physicians I spoke with concur that they observe this as an ever increasing problem, compounded by many factors, for example:

1. Scarce availability for HIV virus genetic analysis, the test for drug resistance. Previously, tests were available through Aga Khan Hospital;(\$405 per test). In 2009, Aga Khan stopped testing, leaving the CDC in Kisumu as the only possible testing site in Kenya. The CDC are research-based and do not wish to do diagnostic testing; nor do they have the capacity to routinely test a large population like Nyumbani's and the surrounding community.

2. In Kenya, NASCOP is the governing body determining HIV/AIDS guidelines. This organization has approved guidelines covering 1<sup>st</sup> and 2<sup>nd</sup> line therapies. Currently, guidelines for 3<sup>rd</sup> line therapies do not exist. PEPFAR, the main donor for ARV therapies, will only send Kenya ARV drugs approved under NASCOP guidelines. At Nyumbani, this means that 4 children are on "salvage" therapy, which is a re-mix of drugs on 1<sup>st</sup> and 2<sup>nd</sup> line.

3. Adherence is an issue likely to continue in economically ravaged populations, per practitioners. New drugs are less dependant on adherence to retain efficacy, which, Sister Mary reminds us, is particularly important for people living in resource-poor communities. Kenya recommends HIV+ patients undergo an annual checkup with CD4 testing, which will track the status of the immune system. By the time CD4 levels identify serious immune depression, there is potential that opportunistic infections can spread through a workplace, or school and threaten health and productivity in a wider community, at a great expense to vulnerable households.

To Sister Mary, the Universal Declaration of Human Rights is a promise. To secure each child's right to live and assist this world reach the best possible future, all children must have fair and equal access to the world's 'spirit of brotherhood' in keeping them alive, per articles 1, 3 & 25. Sister Mary believes the practice for treating pediatric HIV/AIDS in developed countries is best; a proactive resistance test is used in order to identify the correct ARVs for HIV+ children before placing them on antiretroviral therapy (ART); otherwise, standard ARVs may be useless for specific children and they may ultimately die. To this end, Sister Mary lobbied Nyumbani Boards and donors and recently purchased an HIV genetic analyzer to run resistance tests for Nyumbani children and the greater community. The machine will arrive in the late first quarter, or early 2<sup>nd</sup> quarter of 2010. The next steps include refining the training and supplying processes for the machine, which will be housed in the Nyumbani laboratory, thus ensuring that the right medicine is readily available when identified. The cost of the reagents per test will be approx \$200. Getting ongoing funding for the testing will be Sr. Mary's next lobbying task. To this end, Sister Mary has been targeting high profile individuals who are on board and agree to assist: Ambassador Goosby, Global HIV/AIDS coordinator, Medicines for Humanity; supporters and peers are working with drug companies, and suppliers to guarantee appropriate supplies. Nyumbani envisions testing 100+ children per month when their operation is up to potential. The information gathered from these tests will help HIV+ children reach for their future around the world. Sr. Mary, practitioners and Nyumbani supporters believe there is a potential risk of a resistant virus developing in East Africa, an economic hub for the region; if so, it will quickly spread across the continent. Kenya has long experience with ARV and with PMTCT therapy and are on the cutting edge of learning about resistance.

Sister Mary's actions leave me looking into the eyes of my own children and seeing many, many more. How can I tell my boys to take care of themselves while not caring for over 3,000 children? Either children matter, or they don't. There cannot be another discussion

We humbly request the assistance of the Mann Award to facilitate our continuing efforts on behalf of COGRI Nyumbani's children, and their donors and sponsors, which include PEPFAR, Boards in 5 countries and outreach around the world. We envision the Mann Award will enable us to expand our community resistance testing facilities comparable to a developed nation. Expanded capacity allows Nyumbani to save the lives of children immediately impacted with resistance issues and insures their ability to keep HIV+ children healthy and productive. As leaders in the care and welfare of HIV+ children, Nyumbani will continue to collaborate and share information on pediatric HIV/AIDS resistance and treatment, intending to work with all donors, especially pharmaceutical donors, like PEPFAR, pharmaceutical companies and governing bodies, like NASCOP to refine treatments and procure needed drugs. The prestige and recognition of the Mann Award leverages Nyumbani's voice greatly in these arenas. Recognition from this distinguished group signals to all that the Universal Declaration of Human Rights Articles are more than a dream; they are a promise to be taken seriously by people who want the world to remain a place where "acting towards one another in the spirit of brotherhood" is still considered a right, rather than a fashion. To those of us who support this work, this accomplishment for children benefits human kind and adds prestige to The Mann Award.

**Provide specific examples of the work of your nominee in linking health and human rights.**

Please see the above discussion regarding equal access to resistance testing and ARVs for HIV+ children in Kenya.

In addition, Sister is a formidable advocate, and an invited speaker at:

The United Nations NGO Subcommittee on HIV/AIDS. September 30, 2009.

-During her presentation, she demanded free access to ARV therapy for poor populations including access to the more recently developed ARVs.

-She indicated that Kenya needs a Round 9 Global Fund award and strongly advocated that those living under \$1/day not be forsaken by laudable UN humanitarian efforts because of political issues. PEPFAR, Washington, DC. January 7, 2010.

- She demands free access to ARV therapy for poor populations as a right to life.

- She continues to speak candidly regarding the necessity of funding for access to the more recently developed ARVs and resistance testing, even though international organizations may determine that resistance testing is not a priority for developing countries

- She requests Kenya's inclusion in Round 9 of the Global Fund.

**Provide some examples of leadership, creativity and/or courage on the part of your nominee.**

Sister Mary is the Executive Director of COGRI Nyumbani, leading boards in 4 countries and Nyumbani professional staff in their daily operations, with a vision for social justice ensuring every child's right to contribute to the world's solutions.

In Kenya, Sister Mary takes every opportunity to advocate for just governance on behalf of her children:

Caring for HIV Positive Children: Obstacles to the full enjoyment of their human rights. National Forum for Advocacy on Children's Rights, Kenya, 31<sup>st</sup> October, 2009

She relentlessly pursues the Kenyan government to issue birth certificates for orphaned children, fighting unjustified payments and unreasonable delays. If every child has a right to their nationality (Article 15), to Sister Mary it follows that they require a birth certificate. Thinking in this manner is unpopular in Kenya.

Sister Mary and Fr. Angelo D'Agostino (Nyumbani's co-founders), collaborated together and won a landmark anti-HIV/AIDS discrimination lawsuit against the government of Kenya in January 2004, when over 40 children from Nyumbani were denied access to free public schooling a year earlier because of their positive HIV status.

**Provide any other information you think relevant in the selection of your nominee for this Award.**

Sister Mary asks a world of seemingly stretched resources, to look at something uncomfortable. She asks us when will children, who are all born equally innocent into this world, have the same right to live in it? Over 60 years ago, The United Nations Declared this was possible. Sister Mary became impassioned by that promise and continues to inspire

others with her vision. The Mann Award validates and enables this promise. Honoring Sister Mary as this year's recipient perpetuates the ideals of the Mann Award, the United Nations Declaration and saves the lives of children

**What is your relationship to the Nominee?**

I am an inspired admirer. After meeting Sister and community volunteers like her, I founded a small NGO to support the efforts of community leaders like her, who had the audacity to make the downtrodden believe they had a right to dream, and that their dreams were possible. Walking With Angels works with 7 community leaders in Africa. We provide technical support, micro and small grants and capacity building across the sectors our community leaders request our assistance in.