



C.P. 2341, CH-1211 Geneva 2, Switzerland  
Tel: +41 -22- 534 -94 41 (Switzerland)  
[www.Ariana-Leilanifoundation.org](http://www.Ariana-Leilanifoundation.org)  
[CRC@ariana-leilanifoundation.org](mailto:CRC@ariana-leilanifoundation.org)

October 1, 2012

Committee on the Rights of the Child (the CRC Committee)  
Office of the United Nations High Commissioner for Human Rights  
Palais Wilson, Office 2-031  
Geneva, Switzerland email: [registry@ohchr.org](mailto:registry@ohchr.org)

**Submission for OHCHR Report to the Human Rights Council On The Right Of The Child To The Enjoyment Of The Highest Attainable Standard Of Health (article Human Rights Council resolution 19/37); Submission by the Ariana-Leilani Children's Foundation International Coalition**

The following submission is for the OHCHR Report to the Human Rights Council On The Right Of The Child To The Enjoyment Of The Highest Attainable Standard Of Health on behalf of those working to promote the United States ratification of the UN Convention on the Rights of the Child (UN CRC), and the rights of individual children in the USA who experience difficulties in accessing their rights to live through receiving adequate health care, including physical and psychological care.

**The basic premises for the realization of children's right to health**

The Highest Attainable Standard of Health is essential both globally and individually to support the first human right – the right to life –. Anything short of this is inhumane, a denial of human rights, and in conflict with the UN Convention on the Rights of the Child (CRC).

Eradicating widespread disease, access to food and clean water are obvious elements of attainable standard health. However, the basic premises must be more encompassing. The right to the highest attainable standard of health must apply to the individual, not simply at a macro or group level. Thus, the litmus test for whether “the highest standard of attainable health” is a measured for each individual child; otherwise the other principles of the CRC; including non-discrimination, would be compromised and rendered null.

The current life-threatening case of Ariana-Leilani King-Pfeiffer, a nine year old dual German- USA citizen currently living in Washington, DC in the United States, demonstrates the real problems if “the highest standard of attainable standard health” is not applied and measured at the individual level. The German Government has reviewed her current health condition. For over four years Ariana-Leilani King Pfeiffer has been suffering from a treatable life-threatening

disease that has been left untreated with a medicine, (G-CSF) Neupogen that is free to Ariana-leilani which, is being withheld from her. Ariana-Leilani suffers from drug/ “toxin- induced” Severe Chronic Neutropenia (SCN). Yet, to date no toxicology or even urine tests have been done. Severe Chronic Neutropenia is a very rare blood and bone marrow disease that renders the immune system broken, with a severely compromised immune system similar to Acquired Immune Deficiency Syndrome (AIDS). Severe Chronic Neutropenia causes her to risk potentially fatal infections, which when not treated with medicine to boost her immunity, can cause “toxic shock, loss of limbs or loss of life,” according to internationally recognized SCN expert. Ariana-Leilani’s illness is so rare that she has been listed as one of only about 800 people worldwide on the Severe Chronic Neutropenia International Registry (SCNIR) based and Co-Directed in both Germany and the USA. Ariana-Leilani has also been diagnosed with Post Traumatic Stress Disorder (PTSD), which has been left untreated for years. The German Government through its Embassy in Washington, DC has made a formal request to the United States Department of State (Office of Children’s Issues) that the latter assist in securing proper medicine and a full independent medical and psychological evaluation for her conditions. Ariana-Leilani’s life saving needs have also been recognized by international NGO’s, including Innocence in Danger, Worldwide Organization of Women, Children’s Rights International Network, the Severe Chronic Neutropenia International Registry, and CNN Hero Betty Makoni, and her Girl Child Network Worldwide, that champions the human rights of the girl child worldwide.

The US Department of State has claimed that they are unable to help this German-American child within its own territorial borders. Thus, Ariana-Leilani needlessly suffers from her life-threatening health conditions without proper investigative diagnosis and treatment. No doubt if this child were in Germany, her conditions would be actively investigated and treated. The USA’s lack of an effective national legal implementation (ratification) mechanism for the CRC creates a lack of accountability and responsibility for one 9 year old and hundreds of thousands of other children in the USA who do not have access to CRC protections, and thus internationally binding protections.. Ariana-Leilani while in Germany would have her CRC rights recognized, but in the USA there is no recognition of her “rights to the highest attainable health, including life-saving medicine, physical and mental health care. USA recognition of CRC human rights is critical to the safety and life of Ariana-Leilani and others like her. A child, like Ariana-Leilani, with Severe Chronic Neutropenia can “look healthy”, but then could encounter and can succumb to common, but -- to her -- fatal infection within as little as 18 hours – a shorter period than the time it would take for a child to die from loss of access to food.

The question then becomes “who decides and makes the final decision to assure the right to adequate healthcare”? Such situations must be resolved expeditiously to benefit children like Ariana-Leilani at an individual level regardless where the child is living. The “right to health” must be paramount.

**The principles of the CRC must be applied to design, implement and monitor interventions to address childrens rights to the highest standard of attainable health**

The Convention on the Rights of the Child Articles 2, 3, and 6 are particularly helpful in the design, implementation and monitoring of interventions to address children’s and youth health challenge.

Article 2 requires “non-discrimination” no matter where the child lives. Thus, a country may not allow different treatment between children who live in a particular province or town within their country, or between those who live inside and those who live outside of the country of their citizenship. As an example, Ariana-Leilani is being discriminated against receiving the highest standard of attainable health while in the USA because a) she is a German citizen (with only a German passport) currently living in Washington, DC USA, and b) the USA does not have, nor enforces, a uniform national policy for children’s right to health. The German government has recognized its duty to help protect the life of its citizen, Ariana-Leilani, but has thus far been unable to protect her because she is currently living within the boundaries of the non-CRC implementing, United States of America.

Article 3 is also helpful because it spells out that the “best interests of the child” must be the primary concern. It is important to recognize that merely a court “due process hearing” does not satisfy the “best interests of the child”. The “best interests of the child” must be measured against a substantive objective international standard of the world’s countries that have ratified the Convention on the Rights of the Child (CRC), and not an internal country-specific subjective standard. Since the CRC recognizes that children are not property, “parental rights” cannot be allowed to be ownership, and inappropriately override the child’s rights to health. Parental “ownership” is often allowed to subordinate a child’s human rights the highest standard of health. This subordination of a child’s rights to a “parents right” of child ownership, has allowed a parent to deny life-saving treatment, such as it appears to be in the United States of America with Ariana-Leilani.

Article 6 , the individual child’s right to the highest attainable standard of health, specifically that each and every child has a right to live. It would be an abandonment of Articles 2 (non-discrimination) and 3 (best interest of the child) if the requirement in Article 6 were not applied at the individual level. Furthermore, the “right to live” can only be enforced while the child is alive. There can be no retroactive restoration for a lost “right to live.” Thus, the “right to live” requires that preventative measures be taken to avoid any foreseeable fatal consequences. The right to live is violated if adequate preventative measures are withheld or otherwise not provided. Using Ariana-Leilani as an illustration, her right to live is being denied because proper medical evaluation (including toxicology testing) and treatment (including the medicine called neupogen) are being withheld – which will eventually have a fatal consequences if the USA Government authorities do not recognize this individual child’s right to to the highest attainable standard of health.

Article 12, the right to speak and have a say in their lives is essential to enforcement. A child must be allowed the opportunity to speak in their native tongue to an independent neutral listener with whom the child clearly understands that there will be no retribution for the child to speak his/her mind and the truth. It also follows that there must be consequences to the child’s custodian(s) if the custodian takes revenge on the child for having spoken his or her mind. Again, as illustration is Ariana-Leilani, who has told social workers, physicians, psychologists and other forensic interviewers that her father “gives me green medicine that make me sick,” “does bad touch,” “does naughty touch”; “popo gets harder and harder” sleeps in her “big bed”, and that he kisses her “on the lips”. She then told others that her father was hitting her very hard and hurts her, and “he won’t stop.” Government officials have yet to listen to her cries for help. Physical, emotional, and psychological retributions and isolation have taught Arana-Leilani not to speak her mind to others, because no one really cares or feels accountable to her. As a result, she has been effectively silenced over the last four years, not speaking about the present, but only

about her past when her health was better and the abuse, neglect and isolation she endures now was not occurring.

Ariana-Leilani is a dual citizen of Germany and the USA, with a German passport. Germany has ratified the CRC, the United States of America has not. Which member state, Germany or the USA, has the final say for a child like Ariana-Leilani, when her health, and thus life is in danger? Which member state has the final say, when one member state formally recognizes her “right to health” and the other does not? A child, like Ariana-Leilani’s right to the highest standard of attainable health must be of paramount importance. All states must fully and expeditiously cooperate, including the member state in which the child resides (here the USA), and allow that “right to health” to be realized and appropriate care provided. With today’s highly mobile societies and international travel and with all but Somalia and the USA recognizing the CRC, such cross-border situations need to be addressed so that such “rights to highest standard of attainable health” are upheld for all children in all countries no matter where they travel or live.

### **The Obligations and Responsibilities of State and Non-State Actors**

Article 24 provides that children have the right to good quality health care – the best health care possible – to safe drinking water, nutritious food, a clean and safe environment, and information to help them stay healthy. It also provides that rich countries should help poorer countries achieve this standard. However, “rich countries” must not fail to achieve these goals for the children within their own borders. Rich countries must set the example for themselves and others. Children within their borders often come from other countries. It would be particularly ironic if a child from a “poor” country obtained better health care in their own “poor” country than if they were living in the “rich” country that denies its children their basic right to life and their right to highest standard of attainable health.

The failure to provide for children’s right to health is not simply a matter of money or access; it is a question of attitude and basic principles. The USA, a rich country, should be held accountable and not be allowed to ignore children’s rights to health within its borders, simply because it focuses its “aid” and attention on children in other countries. Again, Ariana-Leilani’s health and life struggles illustrate this point. If she were in a “poor” country, the USA would point to the inadequate health care, the discrimination she is being subjected to, and would likely provide aid and incentives to assure that she received the highest standard of attainable health. However, because she currently lives in a “rich” country, the USA, it is uncritically assumed that her medical and psychological needs are adequately met; not because it is so, but because of where she currently lives.

Finally, the responsibility for assuring the delivery of the highest attainable standard of health for individual children and all children must ultimately rest at the national government level. The international rights to the highest standard of health for each child must supersede jurisdictional issues. Certainly Ariana-Leilani’s fight for life, while being denied freely available medicine, is an example of how the CRC is a living document that is essential for the protection of childrens’ lives.

### **Concrete measures and Results of the CRC in Health**

The set of measures for the “highest standard of health” will necessarily vary by country context to correspond to their priorities. However, standard model measures should be adopted

that are able to show the progress towards meeting each country's' priorities. Even though the USA has not ratified the UN Convention on the Rights of the Child, it should be required to demonstrate compliance with the CRC's commitment to each child's "rights to health." Children with dual-citizenship (USA) and other countries that have all ratified the CRC (except the USA and Somalia) and who are within the USA borders must have their human rights, including the "right to the highest standard of attainable health" recognized and protected.

\* \* \*

**Background:**

Under the umbrella of the

**Ariana-Leilani Children's Foundation International**, ([www.ariana-leilanifoundation.org](http://www.ariana-leilanifoundation.org)) a coalition of partners, organizations and individuals who are active in human rights, child protection, with involvement in the NGO CRC Child Health committee and active in International Health issues have contributed to this statement. What unites them is the interest in enforcement of the CRC in all countries, including the USA and throughout the world. It is their hope that children like Ariana-Leilani will cease being denied effective medical care, so that, even in the USA, too, children's "right to health" are protected.

The contributors include:

*Girl Child Network Worldwide* (<http://www.girlchildnetworkworldwide.org/>)

GCNW is an international non-profit organization started by CNN Hero, Betty Makoni. At the centre of a global commitment to gathering, codifying, training and promoting the experiences and expertise of African girl advocates and marginalised girls who are invisible. GCNW mission is to support and promote girls' rights, empowerment, and education by reaching out to and advancing the circumstances of African girls who are economically deprived, at risk of abuse, subject to harmful cultural practices, or living in areas of instability. Daily GCNW helps one girl at a time to reach the top. Their stories inspire us to stay positive and achieve. We believe no one is born victim, we are all victorious. GCNW states, "We Empower And Inspire One Girl At A Time"

*Innocence In Danger Worldwide* (<http://innocenceendanger.org>), an international, non-profit association created by a group of citizens on 15 April 1999, at the initiative of the UNESCO Director-General, Federico Mayor, and under the presidency of Ms Homayra Sellier, in response to the recommendations of the UNESCO expert meeting convened in January 1999 on Sexual Abuse of Children, Child Pornography and Pedophilia on the Internet, in order to pursue the objectives of the Action Plan adopted by the experts to combat sexual abuse of children.

Innocence in Danger operates in 29 countries throughout the world, with partners who share the same objectives.

*Worldwide Organization of Women (WOW)*, <http://www.wowinfo.org>, an international non-denominational, non-profit 501 (c)(3) non-governmental organization (NGO). Since December 1997, the Worldwide Organization for Women (WOW) has held special consultative status with the Economic and Social Council (ECOSOC) at the United Nations. WOW has permanent representatives at both the UN in New York and Geneva. Interns from several universities participate in academic training programs and research focusing on issues affecting women and girls worldwide.