

Geneva, 22 August 2014

Written submission to the 2nd Pre-Sessional Working Group of the Committee on the Rights of Persons with Disabilities

## **LIST OF ISSUES ON THE DOMINICAN REPUBLIC: FAKE AUTISM "CURES"**

Autistic Minority International is a Geneva-based NGO. It is the first and only autism self-advocacy organization active at the global political level. We aim to combat bias and prejudice and advance the interests of an estimated seventy million autistics, one percent of the world's population, at and through the United Nations, World Health Organization, human rights treaty bodies, and other international organizations. Autistic Minority International is an associate member of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO) and a member of the NGO Forum for Health, a Geneva-based consortium of organizations committed to promoting human rights and quality care in global health.

We greatly appreciate the opportunity to be able to provide input for the List of Issues on the Dominican Republic (and the subsequent constructive dialogue with the State Party), but will limit ourselves to discussing and stressing just two interrelated issues with international ramifications, namely medical tourism in search of experimental treatment and the medical and scientific experiments performed on autistic children from abroad in Dominican stem cell clinics and a torturous chemical miracle "cure" peddled by foreign residents of the Dominican Republic to parents of autistic children worldwide. Parents do not act in the best interest of the child when exposing them to the risks and hazards of unproven "therapies" and treatments. The Dominican government called stem cell procedures illegal, and yet they continue to be carried out, apparently without any regulation or oversight. Why has the State Party failed to shut down those clinics? Why does the State Party harbour foreigners involved in international health fraud?

By way of introduction, let us first recall and emphasize that autistic self-advocacy is about more than patients' or disability rights. Autism is a distinct culture and identity. The only one we know. Regardless of where in the world we live, autistics are more like each other than like the people surrounding us. Autism is a neurological difference that is both genetic and hereditary. There is no cure, and we do not believe that a cure will ever be found. The autistic minority includes those diagnosed with Asperger's syndrome and various other conditions on the autism spectrum as well as those children and adults who remain undiagnosed.

In 2007, the United Nations General Assembly declared 2 April World Autism Awareness Day. On that day in 2013, UN Secretary-General Ban Ki-moon wrote: "This international attention is essential to address stigma, lack of awareness and inadequate support

structures. Now is the time to work for a more inclusive society, highlight the talents of affected people and ensure opportunities for them to realize their potential."

In 2012, the United Nations General Assembly unanimously adopted resolution 67/82 "Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities". In this resolution, the UN member states recognize "that the full enjoyment by persons with autism spectrum disorders [...] of their human rights and their full participation will result in significant advances in the social and economic development of societies and communities" and stress "the important contribution that non-governmental organizations and other civil society actors can make in promoting human rights for [...] all individuals with autism spectrum disorders [...] and their integration in societies". The GA voices its concern "that persons with autism spectrum disorders [...] continue to face barriers in their participation as equal members of society" and calls this "discrimination" and "a violation of the inherent dignity and worth of the human person".

As individuals and as a group, autistics continue to be denied the "four key pillars of minority rights", as identified by the UN's Independent Expert on Minority Issues, Ms Rita Izsák: "protection of existence and prevention of violence against minorities; promotion and protection of minority identity; equality and non-discrimination; and the right to effective participation in all areas of public, economic and social life".

Our very existence is in danger as long as autism, without regard to severity, continues to be viewed as something to be eradicated. Violence against us takes the form of behaviour modification, institutionalization, and abusive medical and therapeutic practices, such as electric shocks or stem cell experiments. Instead, we should be taught self-esteem, self-confidence, and how to advocate for ourselves. The autistic minority also includes those of us who hide their condition for fear of discrimination. This is no longer tenable at a time when millions of children diagnosed with autism come of age and many more get diagnosed as adults. Autism awareness must lead to acceptance, recognition, and respect for autistics. Only autism acceptance will ensure our full and equal participation in all areas of public, economic, and social life.

Only autism acceptance will thus meet the requirements of the Convention on the Rights of Persons with Disabilities.

With regard to pseudo-medicine and quackery in the Dominican Republic, we invoke in particular article 15 of the Convention: "No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

"States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment", including medical or scientific experimentation.

According to article 25, "States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. [...] In particular, States Parties shall: [...] Require health

professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through [...] the promulgation of ethical standards for public and private health care".

Also relevant seems article 7 on "Children with disabilities": "States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. [...] In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration. [...]"

"States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right." Parental consent to medical experimentation on autistic children is not sufficient. It is not in the best interest of an autistic child to be subjected to unproven "therapies" or treatments.

Article 3 lists applicable "principles of the present Convention [...]: a. Respect for inherent dignity [...] of persons; [...] d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; [...] h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities."

Finally, article 17 guarantees that "Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others."

There are serious medical conditions – such as cancers of the blood or bone marrow – in which a stem cell transplant might be justified. Autism is not one of them.

A stem cell expert critical of the use of stem cells for autism estimates "that hundreds, perhaps even thousands of autistic children are being infused with stem cells around the world each year"<sup>1</sup>. This although "there is no convincing data to support the idea. [...] [D]octors and clinics promoting stem cell-based 'treatments' for autism today have very little in the way of evidence and frankly sometimes no evidence at all that the treatments will work. The main rationale given by proponents of stem cells for autism [...] is based on the unproven idea that autism is an autoimmune disease and that stem cell interventions will calm down the immune system. The most prevalent stem cell intervention for autism is IV injection of stem cells into the blood stream through a vein in the arm. Absent any real data, this is essentially a long shot, a shot in the dark. And the stem cells given to the children have risks that we do not entirely understand today. Further, those risks may last a lifetime since stem cells, unlike traditional chemical medicines, are alive."

Another sceptical scientist lists stem cells among "the 5 scariest autism 'treatments'" around today<sup>2</sup>, along with chlorine dioxide/Miracle Mineral Solution (MMS) – toxic industrial-strength bleach forced down countless autistic children's throats or injected into the rectum in order to cleanse their intestines of non-existent "parasites" (often applied

<sup>1</sup> <http://www.ipscell.com/2013/11/why-i-do-not-believe-in-stem-cells-for-autism-today/>

<sup>2</sup> <http://www.forbes.com/sites/emilywillingham/2013/10/29/the-5-scariest-autism-treatments/>

multiple times a day<sup>3</sup>) –, chemical castration(!) to lower autistic children's testosterone levels, chelation – a chemical way to strip mercury arguably contained in childhood vaccines from autistic children's blood, but removing all metals, including calcium, which has led to the death of at least one autistic child –, and hyperbaric oxygen therapy (HBOT) – breathing pure oxygen in a pressurized chamber used more commonly to treat decompression sickness in divers or carbon monoxide poisoning and potentially leading to paralysis and air embolisms in autistic children as well as posing a fire hazard that has caused dozens of deaths worldwide. Some parents are so desperate and misguided they will try anything to "cure" their child of autism.

As it happens, the man who "invented" Miracle Mineral Solution (also sold as Master Mineral Solution, Miracle Mineral Supplement, and under other names), Jim Humble – not at all a doctor, but an American mining engineer –, now resides in the Dominican Republic<sup>4</sup>, from where he apparently cannot be extradited despite several people having died due to his procedure. Humble's operational base is the Genesis II Church of Health & Healing, a non-religious worldwide organization headquartered in Barrio Casandra Dameron, Santa Cruz, Barahona, Dominican Republic<sup>5</sup>. At its compound, the "church" runs an MMS training centre, and the ten-day seminars offered include "3 days of treating many locals for all the diseases that they have". According to their website, "[n]o one in the History of Man has had as much ability to heal as many diseases with as much certainty. Medical doctors, for instance, will in their entire lifetime heal less people than one of our Ministers will heal in one month."

In this context, and referring specifically to the MMS scam, chelation, and HBOT, the United States Food and Drug Administration (FDA) released a health fraud alert in April 2014 in which it states unequivocally: "There is no cure for autism. So, products or treatments claiming to 'cure' autism do not work as claimed. The same is true of many products claiming to 'treat' autism. Some may carry significant health risks."<sup>6</sup>

MMS has been banned by the health authorities in many countries<sup>7 8</sup>. Similarly, stem cell treatment for autism – and various other conditions and disabilities, including cerebral palsy, brain damage, spinal cord injuries, muscular dystrophy, cystic fibrosis, multiple sclerosis, Alzheimer's, and Parkinson's disease – has been prohibited by countries the world over. Unfortunately, there are some countries, including the Dominican Republic, Mexico, Panama, Peru, China<sup>9</sup>, India, the Ukraine, Lebanon, and Germany, where stem cell treatment without medical indication or scientific validation can still take place – and affluent parents of autistic children are willing to travel. If MMS caters to the lower end of the market for alternative and unproven autism "cures", stem cells cater to the higher end of the market as such treatments can cost anywhere between 7,000 and 65,000 US dollars per application.

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<sup>3</sup> <http://www.sciencebasedmedicine.org/bleaching-away-what-ails-you/>

<sup>4</sup> <http://www.bancdmms.com/#!about1/c1jyl>

<sup>5</sup> <http://genesis2church.org/churches-worldwide>

<sup>6</sup> <http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm394757.htm>

<sup>7</sup> <http://www.irishexaminer.com/ireland/public-warned-against-us-churchs-industrial-strength-bleach-miracle-cure-275104.html>

<sup>8</sup> <http://www.sott.net/article/216900-Hands-Off-Miracle-Mineral-Solution-MMS-Says-Brunei-Health-Ministry>

<sup>9</sup> <http://www.nature.com/news/china-s-stem-cell-rules-go-unheeded-1.10410>

In 2011, it was reported that the "Dominican Republic's Public Health Minister warned [...] that the clinics which apply treatments based on stem cells risk losing their license, and that he'll instruct regional health officials to notify all of them directly that those procedures are banned.

"Bautista Rojas affirmed that he'll seek to halt the treatments with stem cells until they are authorized by the Bioethics Health Council (Conabios), whose members yesterday stated their concern for the treatments or therapies, noting that those methods aren't proven scientifically, and that their effectiveness in humans is unknown."<sup>10</sup>

A year later, Conabios called such stem cell procedures "a hoax" and cautioned that potential patients, in particular foreigners, should "avoid to be taken as a 'Guinea pig'"<sup>11</sup>.

Despite this, clinics offering stem cells for autism and many other conditions and disabilities continue to operate in the Dominican Republic, and no regulation or oversight appears to be exercised.

The most prominent clinic in the Dominican Republic currently offering stem cell treatment for autism is RegenCenter in Santo Domingo<sup>12 13</sup> (also known as The Stem Cell Project<sup>14</sup> and formerly DR Stem Cell), run by one Gene Anthony, an American naturopath and missionary, and his son, who possesses even less medical credentials. While the website states that all procedures are carried out by specialists at a local private hospital, parents report that in fact Gene Anthony's son had infused their autistic child with stem cells. RegenCenter keeps the exact street address of the clinic a secret.

Other shady Dominican stem cell clinics include Regenocyte<sup>15 16</sup> – headquartered in the United States, but with treatment facilities at an unspecified location in the Dominican Republic (some years ago it was Clinica Union Medica del Norte in Santiago de los Caballeros), where they also treat autistic children – and Regenobody – based in Sosua, Puerto Plata, Dominican Republic<sup>17</sup>, and working with Centro Medico de la Costa Norte and Regenoclinix Health Institute. This list is far from complete.

If adults wish to seek out unproven and hazardous treatment and "therapies" there's little that can be done. But we believe that autistic children must be protected from the consequences of the despair some parents may feel and the scientific and medical experimentation parents will subject them to, even though it is not in the best interest of the child.

Stem cells may be harvested from a child's own adipose tissue and/or bone marrow, requiring anesthesia and surgery. Alternatively, adult donor cells or stem cells from

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<sup>10</sup> <http://www.dominicantoday.com/dr/local/2011/5/24/39647/stem-cell-treatments-illegal-dominicanauthorities-warn>

<sup>11</sup> [http://www.dominicancentral.com/newsarticle/denounce\\_deception\\_with\\_the\\_use\\_of\\_stem\\_cells/](http://www.dominicancentral.com/newsarticle/denounce_deception_with_the_use_of_stem_cells/)

<sup>12</sup> <http://www.regen-center.com/autism.html>

<sup>13</sup> <http://www.lifesitenews.com/news/how-a-small-clinic-in-the-dominican-republic-is-using-adult-stem-cells-to-o>

<sup>14</sup> [http://stemcellscaribbean.homestead.com/HOME.html?\\_=1359003931698](http://stemcellscaribbean.homestead.com/HOME.html?_=1359003931698)

<sup>15</sup> <http://regenocyte.com/the-regenocyte-process.html>

<sup>16</sup> <http://edition.cnn.com/2009/HEALTH/07/14/stem.cell.regenocyte/index.html>

<sup>17</sup> <http://www.regenobody.com/en-stem-cell-clinic.htm>

human umbilical cords or aborted fetuses (and apparently even animals) may be used. Stem cells may be grown in culture prior to transplant, and health risks may arise from a lack of sterility or if their growth is not monitored to ensure that the cells do not change their properties. Most commonly they will be administered intravenously and/or subcutaneously (under the skin). Depending on the kind of stem cells and procedure used the risks for the autistic child include infection, bleeding, trauma, autoimmune reaction, growth of tumors, and cancer.

No one knows how safe stem cell transplants are in the long term, either. Stem cells can grow and increase in number in the child's body. They can and will move around the body, especially if given IV. None of this is natural. For example, abdominal fat stem cells don't just move to an autistic child's brain spontaneously. Very likely nature has a reason for that.

Clearly, the ongoing practices in the Dominican Republic violate multiple articles of the Convention on the Rights of Persons with Disabilities.

Proposed questions on article 15:

Please clarify the official position of the Dominican State Party on medical and scientific experiments performed on autistic children from abroad in Dominican stem cell clinics. Will the State Party commit to enforcing its ban on unproven stem cell treatments and prevent further medical tourism in search of experimental treatment? Will the State Party strengthen regulation and oversight and shut down those clinics? What steps are being taken in particular to make sure the ban is not being circumvented?

Why does the State Party harbour foreigners involved in pseudo-medicine and international health fraud? Will the State Party commit to banning the sale of the torturous chemical miracle "cure" chlorine dioxide/Miracle Mineral Solution (MMS) to parents of autistic children and others worldwide? Will the State Party prevent its use and promotion and any related activities on its territory, particularly those of the non-religious organization calling itself Genesis II Church of Health & Healing?

Thank you for your consideration.

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