NCD Child

Case Studies

ACCESS TO ESSENTIAL MEDICINES AND EQUIPMENT

FOCUS ON CHILDREN AND YOUTH

July 2018

NCD Child

These case studies have been compiled as part of the work of the NCD Child Taskforce on Essential Medicines and Equipment.

All photographs are included with the kind permission of the case study contributor.

A – Child-friendly Rights Flyers

NCD Child founders CLAN empower communities to raise awareness of the need for essential medicines and equipment for children and youth through child-friendly rights flyers

Since 2004 CLAN (Caring & Living As Neighbours) has been learning from communities of children and families living with NCDs in low- and middle-income countries (LMICs) around the world about their challenges, burdens and dreams for change. Very often families are overwhelmed with gratitude for even the smallest offers of assistance, and many are unaware of their children's basic human rights to life and health. As a step towards empowering childhood NCD Communities to advocate for their own needs and purposes, CLAN has worked with a range of community members, stakeholders and other partners to develop a series of child-friendly rights flyers that can be used to raise awareness and advocate for change. Drawing on the United Nations Convention of the Child (UNCRC), the flyers outline specific articles relating to the rights of children living with NCDs to life and health. To date the flyers have been developed with the international Diabetes, Rheumatic Heart Disease, Asthma, Congenital Adrenal Hyperplasia communities, and have been translated from English into Spanish, French, Bahasa Indonesian and Swahili.

[Contributor – Dr Kate Armstrong, CLAN]

Top right image – Young person living with Type 1 Diabetes in Mali presents a Diabetes Child-Friendly Rights Flyer to WHO and Ministry of Health officials at a Diabetes event.
Bottom right image - Excerpt from Child-Friendly rights flyer for Diabetes (English)

B - Prosthetics for Childhood Cancer Survivors

Prosthetics are essential equipment for children and youth cancer survivors requiring amputation – read Kristen's story here

Kristen, a little girl, presented, at three months of age, with a left swollen arm diagnosed as infantile fibrosarcoma, a malignant and potentially aggressive tumor, after clinical investigation, imaging and biopsy. Due to limited capacity of pediatric oncologists, orthopedic surgeons and level of pediatric surgical expertise in St Vincent and the Grenadines, Kristen was enrolled on the World Pediatric Project (WPP). This Project enables teams of medical specialists to visit St Vincent and the English-speaking Caribbean three or four times a year to assess children. WPP facilitated surgical amputation of Kristen's upper left limb in Virginia, USA. Early identification and histological grading of the tumor indicated it was localized and required neither chemotherapy nor radiotherapy after surgical intervention. Now aged 4 years, Kristen's recent review by the visiting WPP surgical team indicates she is doing well. Resources are required to empower our pediatric amputees with modern prostheses and rehabilitative skills to restore function and improve quality of life.

[Contributor – Dr Rosalind Ambrose, St. George's University, Grenada]

Image – Kristen after surgery at 4 years old

C - Asthma - A major public health problem for children and youth in Burundi

Inhalers and spacers are essential medicines and equipment for effective treatment of asthma in children and youth – but what happens if you can't get them?

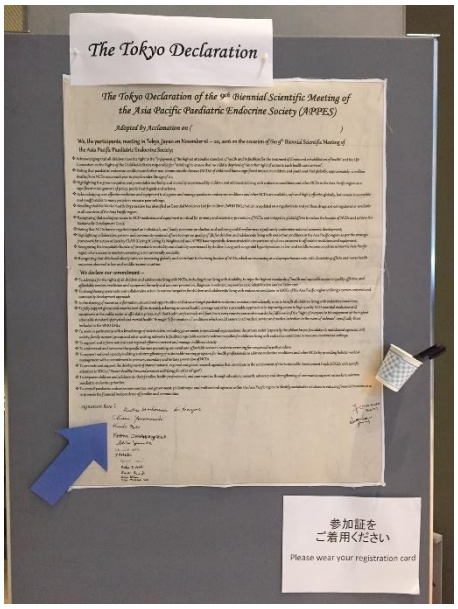
Asthma in Burundi accounts for almost 75% of chronic cough in children. It is estimated that around 10% of all asthmatics in Burundi are aged 5-14 years. Diagnosis of asthma is limited to clinical signs in many healthcare facilities – respiratory specialists who have diagnostic equipment mainly practice in private clinics which limits access. Access to preventive therapies for asthma is limited in Burundi. Beclomethasone spray and Seretide™ disks are available for adults, but pediatric doses are rarely available. Similarly, use of salbutamol nebules is limited to specialist clinics. Spacers are very expensive and thus rarely used. The Burundi NEML does not yet contain salbutamol nebules or pediatric corticosteroid inhalers, and efforts must be made to ensure that medicines on the WHO EMLc and basic equipment (such as diagnostic devices and spacers) are affordably available for use by all. There is an urgent need to strengthen the capacity of health workers in Burundi to diagnose and manage asthma. Government must recognize asthma as a serious public health problem and promote access to diagnosis and treatment for all asthma patients – adult and pediatric alike.

[Contributor – Dr François Ndikumwenayo, Burundi University]

Image – Clinician and young asthma patient

D - Equity for Children Living with Endocrine Conditions –The Tokyo Declaration

Better access to essential medicines and equipment for children and youth will only happen when all stakeholders work together with a common vision. The APPES Tokyo Declaration shows the way.



APPES (the Asia Pacific Pediatric Endocrinology Society) is the main membership body for Pediatric Endocrinologists working in the Asia Pacific region and includes members from approximately 20 countries. In 2015 the ACE (APPES-CLAN Equity) Working Group conducted a snapshot survey of members, with 47 representatives from 12 countries identifying access to essential medicines and equipment as the major priority facing children and adolescents living with a range of NCDs in low- and middle-income countries (LMICs). In response to the survey, APPES members worked collaboratively to develop the Tokyo Declaration. Approved by general consensus at the 2016 APPES Conference in Tokyo by over 400 members and ratified by the Executive Council of APPES in 2017, the Tokyo Declaration offers a roadmap for ongoing efforts to redress inequities for children living with endocrine conditions in the Asia Pacific region.

[Contributor – Asia-Pacific Pediatric Endocrinology Society]

Image – The Tokyo Declaration document

E - A collaborative international approach to updating the WHO Essential Medicines List

The WHO Essential Medicines List for children needs a disease – rather than a product – focus. This UICC review of oncology medicines shows how civil society can lead collaborative updates.

Inequities associated with childhood cancer internationally are stark: survival rates for some cancers are about 80% in high-income countries but as low as 10% in LMICs. Affordable access to essential medicines and quality therapeutic options are major barriers for many. In 2014 the World Health Organization (WHO) approached the UICC (Union for International Cancer Control) to facilitate collaboration within the international oncology community to establish a strategic process for updating their Essential Medicines Lists for adults and children (WHO EML and EMLc). A working group of 14 international experts was convened, and systematically reviewed all cancer drugs on the WHO's EML and EMLc over the next six months. Resultant documents were discussed at a face-to-face meeting with WHO held in Geneva in late 2014, and then submitted for consideration by the WHO Expert Committee in early 2015.This innovative approach by civil society to updating the WHO EML and EMLc offers key insights for other NCD Communities: bring the right experts together to work collaboratively; ensure representation of low, middle and high-income countries – with balanced geographic spread; divide workload into smaller teams for effective use of time and expertise; and circulate final drafts amongst all participants to facilitate consensus.

[Contributor – Dr Ronald Barr, McMaster University]

Image – UICC working group

F - Working collaboratively to promote access to medicines for children in Peru: dismantling barriers to access for fludrocortisone and hydrocortisone tablets

When health professionals, health authorities, patient groups, NGOs and international specialist societies demand better access to medicines for children and youth with one voice, results are amazing, like GPED's work in Peru.

Congenital Adrenal Hyperplasia (CAH) is the most common adrenal condition of childhood, requiring lifelong access to hydrocortisone and fludrocortisone tablets. Despite both drugs being on the Essential Medicine List for Children (EMLc), neither medicine is registered in Peru and families must source the medicine through unsustainable pathways (e.g. the black market or the internet). International consortium Global Pediatric Endocrinology and Diabetes (GPED) has been working actively with partners within and beyond Peru to understand the challenges and barriers to accessing CAH medicines. Approaches to Merck Pharmaceutical Company nationally and internationally resulted in the successful national registration of fludrocortisone in May 2017, but by April 2018 local access had still not been achieved. Ongoing efforts are underway to better understand the barriers. The plight of families affected by CAH in Peru highlight the challenges communities face when essential medicines needed to manage NCDs do not offer profitable business propositions for pharmaceutical companies. Engagement of health professionals, health authorities, patient groups, non-profit organizations (NGOs) and international specialist societies and colleagues is key to success.

[Contributor – Dr Jean-Pierre Chanoine, Global Pediatric Endocrinology and Diabetes]

G - Rheumatic heart disease and the antibiotic benzathine penicillin G

When pharma stops manufacturing life-saving medicines like benzathine penicillin G for rheumatic heart disease because of low volumes and margins, children and youth are at risk.

Of the 33 million people around the world living with rheumatic heart disease (RHD), the vast majority are in LMIC. The remainder are vulnerable populations in high-income settings including Indigenous communities, refugees and migrants. Without treatment RHD causes heart failure and increases the risk of stroke, heart rhythm abnormalities and complications during pregnancy. RHD is a post-infectious cause of chronic heart disease of adolescents and young adults. Regular antibiotic injections of benzathine penicillin G (BPG) can slow the progression of heart valve disease in RHD. Injections must be given monthly to prevent Strep A infections which cause the abnormal immune response underlying RHD. Antibiotic prophylaxis needs to be given for up to a decade during the high-risk adolescent period to be effective. All forms of BPG have been subject to shortages over the last decade, causing disruption in treatment for people who need regular BPG injections to stop progressive damage to their heart valves. Market analysis by the Clinton Health Access Initiative confirmed that a number of manufacturers for the active pharmaceutical ingredient of BPG stopped producing the product because of low volumes and low profit margins. A global strategy to secure BPG supply for people with RHD in low-resource settings is important for ending RHD and to ensure the best use of effective antibiotic medication.

[Contributor – Dr Rosemary Wyber, RhEACH, Telethon Kids Institute]

Image – Rural Youth
(Life for a Chiild / International Diabetes Federation)

H - National and regional approaches to the prevention of cervical cancer: inclusion of the 4-valent Gardasil™ vaccine in the immunization schedule for children in Barbados

Want to know how pooled procurement and a Revolving Fund help 40 Latin American and Caribbean countries to protect young women from cervical cancer?

In Barbados, cervical cancer is recorded as the third most common cause of death in women, with Human Papillomavirus (HPV) recognized as causing almost all such cervical cancers. In January 2014, the Barbados Ministry of Health introduced the HPV vaccine for all 11 and 12-year-old secondary school girls as part of the national primary cancer prevention policy. The vaccine is procured through the Revolving Fund for vaccine procurement of the Pan American Health Organization (PAHO). This fund is a mechanism for the pooled procurement of vaccines. As of March 2016, 40 Latin American and Caribbean countries - including Barbados - have signed agreements with PAHO to use the Fund. By pooling demand and purchasing for numerous countries at the same time, the Fund is able to achieve economies of scale and offer products at highly competitive prices. The Revolving Fund generally buys vaccines on an annual tender and is funded almost entirely from national budgets. In Barbados the Ministry is presently embarking on a new campaign to educate the population on the importance of the full course of the vaccine to improve the second dose uptake. Use of the existing national cancer registry will strengthen data available to evaluate the vaccination program and its capacity to increase immunization rates amongst vulnerable populations.

[Contributor – Dr Paula Michele Lashley, University of the West Indies]

J - Access to medicines for children and youth with type 1 diabetes in Tanzania – a personal account by Johnpeter Mwolo, patient and T1International advocate

Making insulin affordable is literally a matter of life or death. Why should youth spend precious time touring pharmacies? Government and pharma need to get creative…

"As a child with type 1 diabetes in Tanzania, life is difficult due to lack of availability of personal glucose machines. Other supplies, like urine strips and glucagon injections, are not found in many hospitals. The availability of HbA1c kits is also a problem. Recently, I was having life-threatening low-blood sugar episodes. I looked for the glucagon emergency injection everywhere, but it practically does not exist here. Thanks to a friend visiting from New Zealand, I was able to get one, but once it expires I am out of luck. My doctor also prescribed a newer insulin to help stabilize my blood sugar levels. I spent days searching for that insulin and could not find it in any pharmacies. I finally found a pharmacy that had it, but the cost was $25 USD, which is completely unaffordable because I need at least one vial per month. Pharmaceutical companies need to work harder to provide essential insulin and supplies at genuinely affordable prices, and to create solutions that ensure they reach rural areas. Education for healthcare professionals about the signs and symptoms of diabetes is needed. The government must ensure affordable treatment is available, and that there are more diabetes specialists throughout the country."

[Contributors – Johnpeter Mwolo / Elizabeth Rowley / T1International]

Top left image – Aseptic production work

Bottom right image – Insulin products

K - UHC in Sri Lanka – Improving access and affordability

Sri Lanka is a beacon of hope showing NEML essential medicine availability at 80-90% within its universal health coverage system, benefiting all age groups. How has the country done it?

The Sri Lankan NEML contains 20 essential medicines that the government aims to make freely available to all citizens within universal health coverage (UHC). The Sri Lankan government reserves the necessary funds to buy medicines in its annual budget. Availability of the NEML medicines is currently 80-90%. The government runs a central procurement system. Sri Lanka imports medicines from countries like India, Bangladesh and even western countries using WHO approval processes for drug purchases. The Sri Lankan Ministry of Health prepares the National essential medicine list for NCD management using WHO EML drugs. Currently more than 90% of the NEML drugs are available - this is the percentage of institutions with one month's buffer stock - in the government sector free of charge to citizens. There is no real problem with counterfeit drugs because of a strong regulatory system. By making medicines accessible and affordable, the black market becomes irrelevant. Applying a government-controlled price to 48 NCD medicines, has been very effective, reducing costs by 50%. Provision of expensive cancer drugs, cardiac stents, bypass and transplant surgeries, eye lenses etc. free of charge helps to improve citizens' health. Government engages with the private sector to achieve affordable access. There is also a tax concession for pharma. This encourages the industry to engage and invest in the country, improving employment as well as EME availability and price if the medicine is only produced in Sri Lanka.

[Contributor – Dr Thilak Siriwardana, Ministry of Health, Sri Lanka]

L - Challenges in securing blood glucose monitoring supplies

It's not just about medicines – affordable glucose meters and monitoring strips are essential equipment that can help children and youth with Type 1 diabetes to manage their condition.

It is estimated that 1.1 million children and adolescents have type 1 diabetes (T1D) worldwide. Management includes daily insulin and self-monitoring of blood glucose (SMBG), plus clinical care. In less-resourced countries, it can be challenging for those with T1D to access insulin and clinical care. Provision of SMBG supplies is even more difficult. Resultantly, most with T1D must purchase supplies out-of-pocket at private retail pharmacies, where even two test-strips/day can outweigh annual insulin costs and consume a high proportion of GNI per capita. Without SMBG, youths risk dangerous glucose levels and complications. Some health insurance schemes in Low- income countries and several national health systems in Upper-middle income countries have made progress in providing SMBG supplies. Some companies help with donation programs. There are efforts to develop low-cost SMBG systems. However, on a comprehensive scale, SMBG supplies are inadequately provided and infrequently used by youths with T1D in less-resourced countries. In order for health systems to provide SMBG supplies, we advocate that test-strips be included in future iterations of the WHO Model List of Essential In Vitro Diagnostics. It is also crucial that as technological advancements continue in the glucose monitoring, affordable blood glucose meters and strips must remain available.

[Contributor – Life for a Child / International Diabetes Federation]

Image – Parent and Child with testing strips

M - Understanding the burden of Nodding Syndrome in Uganda

Have you heard of Nodding Syndrome? Maybe not – but you need to read how families, their doctors and the media convinced a Government to invest in essential medicines for children and youth.

Nodding Syndrome is a chronic debilitating disease of childhood (onset between the ages of 5-15 years) of unknown cause. Nodding Syndrome is characterized by seizures and weakening of muscles, resulting in the signature lolling of the child's head on the shoulders (which gives the condition its name). Acknowledging the imperative of engaging members of the Nodding Syndrome Community in driving solutions, doctors in Northern Uganda first worked to conduct a Health Needs Assessment to better understand the challenges, concerns and priorities of the Nodding Syndrome Community. A survey of 50 families was commenced in November 2017, with time given for families to express their feelings and thoughts about what they needed most to have a better life. Of note, virtually every single family surveyed - regardless of family income, education level, or proximity to health facilities - identified challenges accessing essential medicines as a key concern. Involvement of journalists and the media have proved vitally important, with the Prime Minister of Uganda committing 1.3 Billion UGX (USD$350,000) to Nodding Syndrome in early 2018 to support national efforts to enhance diagnostic, therapeutic and preventive measures. Ongoing efforts to connect, support and empower the Nodding Syndrome Community of Uganda are underway, with equitable and affordable access to all medicines in the WHO EMLc a major priority.


Govt sets aside sh1.4b for nodding disease

[Contributor – Dr Andrew Twineamatsiko, Nodding Syndrome Project, Uganda]

Left image – The project team – L-R - Dr Twineamatsiko, Kiiza Jimmy & Tumusiime
Right image - National newspaper New Vision (22/3/2018) announcing funding for Nodding Syndrome treatment

N - Securing fludrocortisone treatment for Algerian children and adolescents living with CAH

The voice of children, youth and families who need essential medicines is a powerful force for influencing national Governments. Are your families empowered as advocates?

Around 1000 children and adolescents with congenital adrenal hyperplasia (CAH) are presently followed in Algeria, a number that is likely driven by the high rate of consanguinity in the country (>25%). The essential medicines for this chronic condition include hydrocortisone and fludrocortisone. The National list of medicines for Algeria includes

tablets of hydrocortisone, which are readily available in pharmacies and covered by the quite generous Algerian Health system. In contrast, it does not include tablets of fludrocortisone. However, fludrocortisone is included in the list released by the Pharmacie Centrale des Hôpitaux (PCH) in Algeria. Practically, this means that a non-registered product can be imported in Algeria and covered by the National Health system, provided that a request is sent to the Ministry of Health and that suitable pharmaceutical companies are identified. Dr Asmahane Ladjouze and Dr Chanoine (Global Pediatric Endocrinology and Diabetes, GPED) organized the first group meeting for parents of children with congenital adrenal hyperplasia (CAH) in Algiers in November 2015. There were many questions from parents. The Government representative who attended was very interested by this information and very positive about the potential of getting access to fludrocortisone. A parent volunteered to be the contact for all families and to provide support for other parents. However, as of February 2018, this had not led to the development of an official CAH parent group in Algeria. However, Dr Ladjouze has published an article in an Algerian newspaper, contacted the families again and written to the new representative of the Government in March 2018.

[Contributor – Dr Jean-Pierre Chanoine, Global Pediatric Endocrinology and Diabetes]

Left image - First meeting of the CAH parents group in Algeria

P - Successful Journey Towards Availability of Hydrocortisone in Indonesia

Having to import essential medicines? Read how Indonesia secured its own sustainable manufacturing base for hydrocortisone tablets that will benefit its children and youth.

After more than a decade of struggle, hydrocortisone tablets are now produced and available in Indonesia. From early 2018, hydrocortisone tablets (Genisone™) have been produced by the Indonesian company Indofarma and are now available in larger cities in Indonesia. In 2010, in collaboration with APPES, CLAN and colleagues in Pakistan, a submission was made to the World Health Organisation (WHO) requesting hydrocortisone be included in its Essential List of Medicines for Children (EMLc). Soon after, the Pediatric Endocrinology working group of the Indonesian Pediatric Society was working closely with Indofarma, an Indonesian Government owned pharmaceutical company, regarding the possibility of local hydrocortisone production. Indofarma committed to produce hydrocortisone, however, significant time was needed to navigate complex internal factors at Indofarma and other bureaucratic issues. In 2014, Dr Aman Pulungan, as head of the Indonesian Pediatric Society (IDAI), successfully petitioned the Indonesian National Agency of Drug and Food Control to approve hydrocortisone for urgent production, however, time was still needed for initial experimentation and quality testing. Finally, at the beginning of 2018 Indofarma-produced hydrocortisone was in the market. We are delighted that hydrocortisone is now produced and available in Indonesia and we hold great hope that fludrocortisone will also be produced in Indonesia in the future.

[Contributor – Dr Aman Pulungan, Indonesian Pediatric Society]

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