

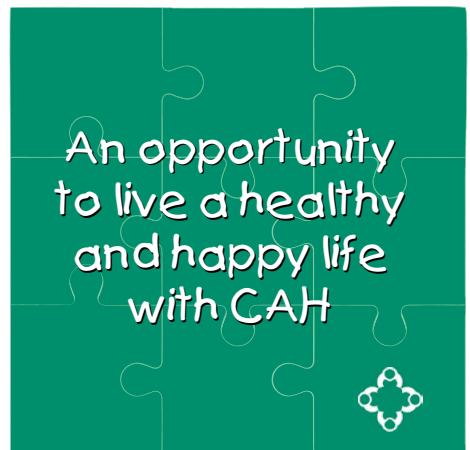
# What are the Rights of the Child Living with Congenital Adrenal Hyperplasia (CAH)?

**All children around the world should have, or be able to have the same rights. These rights are provided for by the United Nations Convention on the Rights of the Child (UNCRC) 1989.**

The United Nations recognises that as a child you should be fully prepared to live an individual life in society and be brought up in the spirit of happiness, love, understanding, peace, dignity, tolerance, freedom, equality and solidarity.

CAH is the most common adrenal condition of childhood. As a child living with CAH, you have the right “to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health”. It is the responsibility of the international community to ensure that countries “strive to ensure that no child is deprived of his or her right of access to such health care services”.

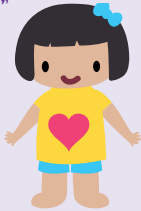
Children, young people and their families living with CAH and other chronic health conditions in low- and middle-income countries ask for help with five key action areas (CLAN's Five Pillars). Fortunately, UNCRC recognises these needs as the rights of children.



## What do families and young people living with CAH ask for?

## Your rights and responsibilities under the United Nations Convention on the Rights of the Child (UNCRC)

"We need affordable access to medicine and equipment"



- The inherent right to life (Article 6).
- Governments recognise that a child living with a mental or physical disability should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate your active participation in the community ... and ensure access to health care services and rehabilitation services (Article 23).
- The right to the enjoyment of the highest attainable standard of health and facilities including the provision of necessary medical assistance and health care (Article 24).

"We need more education, research and advocacy"



- The right to express your views and be heard in judicial and administrative proceedings that affect your rights (Article 12).
- Governments shall respect the rights and duties of parents and legal guardians to provide direction to you in the exercise of your rights as you grow up (Article 14).
- The right to information and material aimed at promoting your physical and mental health and to ensure appropriate guidelines to protect you from information and material that is injurious to your wellbeing (Article 17).
- The right to be informed, have access to education and be supported in the use of basic knowledge of child health and nutrition (Article 24).
- The right to education directed at the development of your personality, talents and mental and physical abilities to the fullest potential and the development of respect for human rights and fundamental freedoms (Article 29).
- Governments commit to making your rights in UNCROC available to you (Article 42).

"All kids need access to good quality health care"



- The right to preserve your identity, including nationality, name and family relations... Where you are illegally deprived of some or all elements of your identity, governments shall provide appropriate assistance and protection, with a view to speedily re-establishing your identity (Article 8).
- Governments shall ... ensure the development of institutions, facilities and services for your care (Article 18).
- Governments recognise that a child living with a mental or physical disability should enjoy a full and decent life...and opportunities in a manner conducive to you achieving the fullest possible social integration and individual development (Article 23).
- The right to a standard of living adequate for your physical, mental, spiritual, moral and social development including material assistance and support programs (Article 27).

## What do families and young people living with CAH ask for?

## Your rights and responsibilities under the United Nations Convention on the Rights of the Child (UNCRC)

"Family support group meetings help us a lot"



- You and your family have the responsibility to help you learn to exercise your rights (Article 5).
- The right to freedom of association (Article 15).
- Governments recognise that a child living with a mental or physical disability should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate your active participation in the community...and the right of the child living with a disability to special care, subject to available resources, for you and those responsible for your care (Article 23).
- The right of a child to rest and leisure, to engage in play and recreational activities (Article 31).

"We are poor - my family needs financial independence"



- Governments shall undertake all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the present Convention ... to the maximum extent of their available resources and where needed, within the framework of international co-operation (Article 4).
- The right to benefit from social security, including social insurance (Article 26).
- The right to a standard of living adequate for your physical, mental, spiritual, moral and social development (Article 27).
- The right to education (Article 28).



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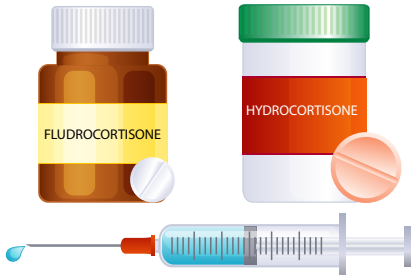


#CAHCommunityLinks #EVERYchild #LeaveNoChildBehind #Access2Medicines

CLAN (Caring & Living As Neighbours) is an Australian non-government organisation committed to equity for children and young people living with CAH and other non-communicable diseases (NCDs) in low- and middle-income countries (LMICs). Families CLAN works with consistently request collaborative focus around five key pillars to help their children enjoy the highest quality of life possible. These five pillars are the intellectual property of CLAN.

Further information about CLAN's community development approach is available at [www.clanchildhealth.org](http://www.clanchildhealth.org).  
For more information on the United Nations Convention on the Rights of the Child (UNCRC) please visit [www.unicef.org/crc](http://www.unicef.org/crc)

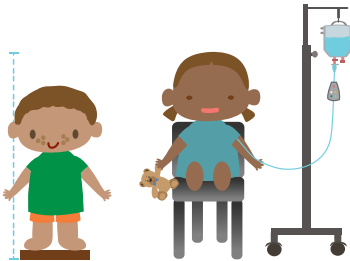
# What do Children Living with CAH Need to Live a Happy and Healthy Life?



EVERY child living with CAH should have affordable access to hydrocortisone and fludrocortisone tablets and hydrocortisone injections. These drugs are on the WHO Essential Medicine List for Children.



All families should have access to information on CAH in their own language and to a trained health professional. Research on CAH is also important.



Children living with CAH must visit their doctor for regular check-ups. They also need access to emergency treatment on sick days.

## CAH SUPPORT GROUP



The chance to connect with other people who are living with CAH for support and encouragement helps children and families learn and grow as a community.



Every child with CAH should enjoy a fulfilling life, free from social stigma and isolation. Every child with CAH should attend school and have the opportunity to play sports.



CAH can be easily diagnosed with heel-prick testing of newborn babies. The test is cheap, safe, accurate and saves lives by diagnosing CAH early.