

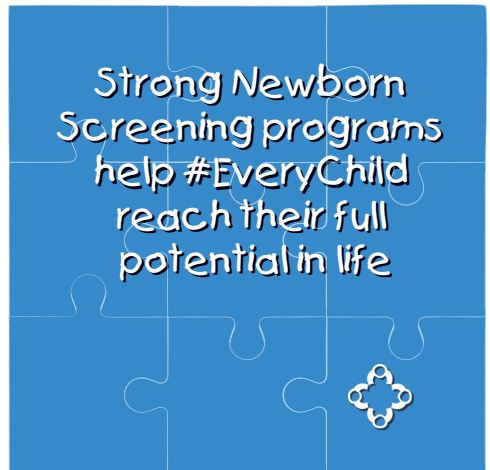
What are the Rights of Children to Newborn Screening (NBS)?

All children around the world have equal rights. These rights are declared by the United Nations Convention on the Rights of the Child (UNCRC) 1989. The international community has obligations to ensure no child is deprived of his or her rights, including access to health care services.

The United Nations declares all children must be fully prepared to live an individual life in society and brought up in the spirit of happiness, love, understanding, peace, dignity, tolerance, freedom, equality, and solidarity.

#EveryNewborn baby has a right to achieve their full potential in life. NBS detects conditions that, when diagnosed early, can be treated to prevent disability and death. NBS is available to #EveryNewborn in high income countries, and is an important part of a strong healthcare system. In most lower income countries however, NBS is not available at all. Only 30% of the 140 million babies born around the world each year receive some screening. This is not acceptable.

The World Health Organisation states that all children have the right to “the highest attainable standard of health” and wellbeing without discrimination. Children living with chronic health conditions have these rights too! Children, young people and families living with chronic health conditions in lower income countries ask for help with five key action areas (CLAN's Five Pillars). UNCRC recognises these needs as the rights of all children..



Strong NBS Programs care for children diagnosed with chronic health conditions!

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(1)).
- Governments will ensure the survival and development of the child (Article 6(2)).
- Governments recognise that a child living with a disability will enjoy a full and decent life in conditions which ensure dignity, promote self-reliance, and facilitate active participation in the community... and ensure equal access to health and rehabilitation services (Article 23).
- The right to the enjoyment of the highest attainable standard of health and wellbeing without discrimination, and facilities including the provision of necessary medical assistance and health care (Article 24(1), (2)(b)).
- Governments shall take appropriate measures to diminish child and infant mortality (Article 24(2)(a)).
- Governments shall take appropriate measures to develop preventive health care and guidance for parents (Article 24(2)(f)).

“We need more
education, research
and advocacy”



- All children will be provided these rights irrespective of whether they live with a disability (Article 2).
- The right to express your views and be heard in judicial and administration proceedings that affect your rights (Article 12).
- The right to information and material that promotes physical health and mental wellbeing, and safeguards that protect you from information and material that is injurious to your wellbeing (Article 17).
- Governments will consider families financial resources and, where possible, extend assistance to children living with disabilities to ensure access to education (Article 23(3)).
- The right to be informed, have equal access to education, and be supported in the use of knowledge of child health and nutrition (Article 24(2)(e)).
- The right to education that facilitates equal opportunity and experiences and ensure that all children with disability can fulfill their potential as equal citizens (Articles 28 and 29).
- Governments will make sure your rights are widely known to adults and children alike (Article 42).

“All kids need access to
good quality health care”



- Governments will assist parents in the caring of their children through the development of institutions, facilities and services (Article 18).
- Children who have disability will receive special care and support so that they can live a full and independent life... with opportunities and experiences that ensure all children and their families can fulfill their potentials as equal citizens (Article 23).
- Governments will consider families financial resources and where possible extend assistance to children living with disabilities to ensure access to health care (Article 23(3)).
- The right to a standard of living adequate for your physical, mental, spiritual, moral, and social development... including through material assistance and support programs (Article 27).

Strong NBS Programs care for children diagnosed with chronic health conditions!

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

"Family support group meetings help us a lot"



- Governments will respect the rights and responsibilities of families, extended families, and communities to guide children so that, as they grow up, they learn to use their rights properly (Article 5).
- Children who have disability will receive special care and support so that they can live a full and independent life... with opportunities and experiences that ensure all children, and their families can fulfill their potentials as equal citizens (Article 23).
- Children have a right to rest and leisure, to engage in play and recreational activities and to participate in cultural life and the arts. Governments shall encourage equal opportunities for these activities (Article 31).

"We are poor - my family needs financial independence"



- Governments shall undertake appropriate measures for the implementation of these economic, social and cultural rights to the maximum extent of their available resources (Article 4).
- State Parties will consider families financial resources and where possible extend assistance to children living with disabilities to ensure access to health care (Article 23 (3)).
- Children have the right to benefit from social security, including social insurance (Article 26).
- The right to a standard living adequate for your physical, mental, spiritual, moral, and social development (Article 27).
- All children have the right to education without discrimination (Article 28).



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cah-international.org



pscrp.org.pk



caresfoundation.org

CLAN (Caring & Living As Neighbours) is an Australian non-government organisation committed to equity for children and young people living with NBS 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.

For more information on the United Nations Convention on the Rights of the Child (UNCRC) please visit www.unicef.org/crc
References: Ragen, J. (2022) The Risk of Good Intentions. Navigating outcomes for people with disability. Sydney University, Sydney, Australia.

#EveryNewborn #NewbornScreening #EveryChild #INSD #LeaveNoChildBehind #PKU #G6PD

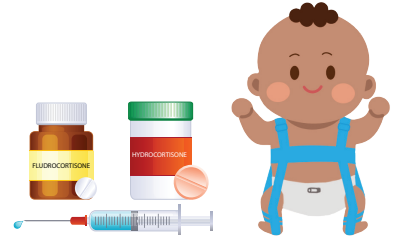
#Access2Medicines #WeAreCAH #CongenitalHypothyroidism #CongenitalAdrenalHyperplasia

#HearingImpairment #Retinoblastoma #SickleCellDisease #ChildRights #NBS #Equity #HumanRights

Strong NBS Programs Care for #EveryNewborn!



Every baby is screened at birth for congenital health conditions so treatment and support can be started early. Strong newborn screening programs include: a whole body "head-to-toe" physical examination; hearing and eye checks; pulse oximetry (checking oxygen levels for heart disease); and a heel-prick blood test.



Families of every baby diagnosed with a chronic health condition through NBS can affordably access the essential medicines, supplements and equipment their child needs to survive and thrive.



NBS heel prick blood tests are processed and followed up in a timely way, so that #EveryNewborn with a treatable condition can survive and thrive.



Healthcare professionals are trained and resourced to screen #EveryNewborn and provide quality healthcare to all babies diagnosed through NBS.

SUPPORT GROUPS



Support groups are available to help children and families living with newly diagnosed chronic health conditions



Informational resources on NBS and all of the conditions screened for are available to promote awareness and support education, training and empowerment for all.

28 June is #InternationalNeonatalScreeningDay

Let's celebrate the birthday of Dr Robert Guthrie and #INSD together each year!