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R HealthBeat

Health Magazine Vol.37, June 2024.

Beyond What We See

Celebrating Strengths & Embracing Differences

What do you Need to Know about Inclusion in Education?

Does Health Insurance Cover all The Congenital Diseases in India?

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In this edition of RHB, we embark on a poignant journey, exploring the resilience and determination of children born with congenital diseases and the unwavering support of their families. Under the theme ***"Beyond What We See",*** we shine a light on the challenges these courageous individuals face and the collective strength that binds them together.

Each day, countless families confront the realities of raising children with congenital diseases, navigating through medical complexities, societal barriers, and the uncertainty of the future. From Thalassemia to Congenital Heart Diseases, Albinism, Autism, and Down Syndrome the spectrum of challenges is vast, yet their voices echo a singular message of hope, courage, and perseverance, not as a presumed failure.

Through heartfelt narratives and real-life stories, we honour the indomitable spirit of these young fighters who defy the odds and inspire us with their resilience. Their stories serve as a testament to the power of the human spirit and the unwavering determination to overcome adversity.

Amidst the medical challenges and hardships parents face, it's essential to recognize the pivotal role of support systems, including healthcare providers, caregivers, and advocacy groups. Together, they form a formidable force, offering solace, direction and priceless resources to families navigating the complexities of congenital diseases.

As we delve into the intricacies of each condition, we are reminded of the urgent need for increased awareness, accessibility to healthcare services, and inclusive policies that ensure every child receives the care and support they deserve. Our collective efforts must be directed towards fostering a more inclusive society where individuals of all abilities are embraced and empowered to thrive, championing their cause, and advocating for better healthcare infrastructure.

At Reliance General Insurance Company Limited, we are committed to supporting families facing the challenges of congenital diseases. We strive to provide the necessary support and resources to ensure every child receives the care they need to lead a fulfilling life.

Together, let us amplify their voices, celebrate their triumphs, and reaffirm our collective commitment to building a more compassionate and inclusive world.

Wish you the best of health... always!

BEST REGARDS,

RAKESH JAIN

CEO, RGICL

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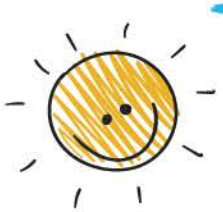
CONTENT



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Can Prenatal Stem Cell Therapy Cure the Incurable Before Birth?

Early treatment for inherited diseases, including prenatal stem cell therapy, could lead to better quality of life and lower healthcare costs. Prenatal stem cell therapy is showing potential for treating a range of diseases. This article covers the past, present, & future of prenatal stem cell therapy, as well as the obstacles and possible new strategies for addressing severe illnesses.

Introduction

The history of prenatal stem cell therapy started with the discovery of embryonic stem cells (ESCs) in the late 1990s, which can transform into any cell in the body. However, ethical concerns led to the exploration of alternative sources like amniotic fluid stem cells and umbilical cord blood stem cells. Amniotic fluid stem cells (AFSCs) are pluripotent and have low immune rejection, while umbilical cord blood stem cells have great regenerative abilities and are easy to collect.

Below are common genetic disorders that can be screened:

1 Embryonic Stem Cells (ESCs)

come from early embryos and can become any cell type, but are controversial due to ethical concerns surrounding the destruction of embryos during the extraction process.

2 Amniotic Fluid Stem Cells (AFSCs)

come from the fluid around a developing fetus, are limited in the types they can become, and have a lower tumour risk than ESCs.

5 Foetal Stem Cells

come from developing fetus tissues and can help with neurodegenerative disorders and congenital abnormalities.

3 Umbilical Cord Blood Stem Cells (UCBSCs)

are collected after birth and are used to treat blood-related disorders.

4 Induced Pluripotent Stem Cells (IPSCs)

get transformed from adult cells, such as skin cells, using gene introduction or other techniques. These cells are similar to embryonic stem cells but are derived from the patient's cells, reducing the risk of rejection and ethical concerns associated with using embryos.

Different types of stem cells have specific advantages & limitations that impact their use in prenatal stem cell therapy. Animal studies have shown the effectiveness of this therapy for various diseases, with promising outcomes such as tissue repair and improved survival rates. Clinical trials have also shown positive results in treating conditions like spinal muscular atrophy and cerebral palsy, with improved motor skills and extended survival seen in patients.

Diagnosing genetic diseases before birth

Many genetic diseases can be diagnosed in the fetus using DNA from chorionic villus sampling or amniocentesis. Testing is usually done when parents are carriers or have a family history of the disease, and treatment varies depending on the condition, with some being treatable with stem cell transplants.

Utero hematopoietic stem cell transplantation (IUHCT) is a method developed to address challenges of postnatal transplantation by treating genetic diseases during pregnancy. IUHCT offers advantages over traditional bone marrow transplants, including decreased rejection of donor cells and the potential for curing certain genetic conditions definitively. The fetal stage allows for successful graft acceptance, offering hope for treating a range of inherited defects like Thalassemia and Immunodeficiency diseases. Human research is ongoing, with successful applications limited to a few diseases, such as alpha thalassemia major.

Fetal intervention before birth

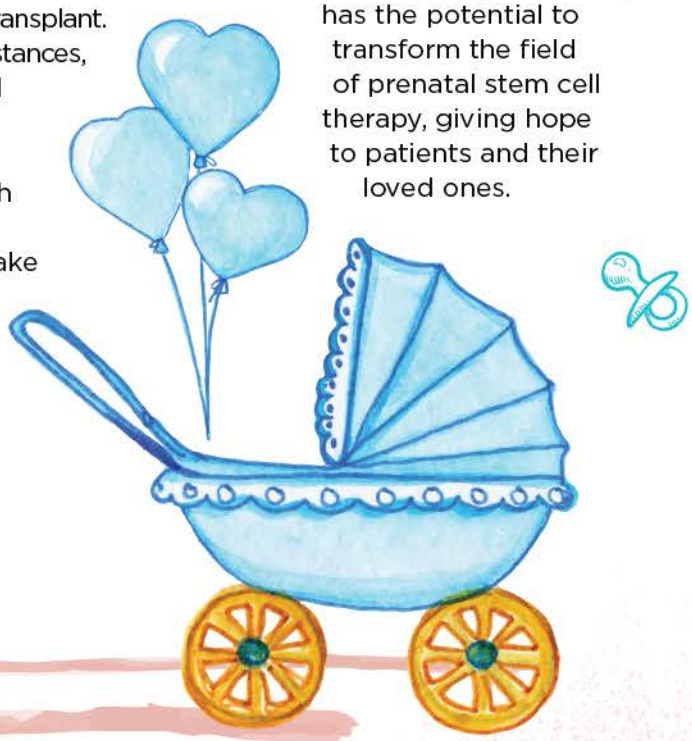
In certain genetic conditions, it may be beneficial to intervene before birth to prevent ongoing damage to the fetus and potentially improve the outcome of hematopoietic stem cell transplantation. In utero stem cell transplantation could take advantage of fetal immunologic immaturity, avoiding the need for immunosuppression or myeloablation. However, there are risks involved, such as infection or the transplant not being successful, so careful consideration is necessary before attempting this new therapy.

What will happen after birth?

The treatment approach for newborns with genetic conditions may vary based on the specific condition. In some cases, post-birth planning may involve hematopoietic stem cell transplantation, such as a bone marrow transplant. In certain circumstances, a repeat stem cell transplantation from the same donor after birth might be considered to take advantage of existing immunologic tolerance.

What does the future hold?

Researchers are looking into new methods like induced pluripotent stem cells (iPSCs) to address the future of stem cell therapy. iPSCs involve reprogramming adult cells to act like embryonic stem cells, which could provide a personalized and ethically acceptable source of stem cells with lower risks of rejection. Additionally, gene editing technologies like CRISPR-Cas9 offer the possibility of correcting genetic abnormalities in prenatal stem cells,potentially leading to customized treatments| for patients. Prenatal stem cell therapy shows promise in treating serious illnesses and birth defects, with recent progress in alternative sources such as AFSCs and UCBSCs. Ongoing research into innovative approaches like iPSCs and gene editing has the potential to transform the field of prenatal stem cell therapy, giving hope to patients and their loved ones.



What's in a Color?

"At 7 years old, I saw small patches on my skin that spread by age 11, indicating Vitiligo, a rare autoimmune skin condition causing light patches due to melanin loss. Although it can appear anywhere, it often shows on the face, neck, hands, arms, and legs." Ravi, 35, shared his experience living with Vitiligo.*

Namitha, 31, and husband Rahul*, 33, were surprised to find out their 10-month-old twin had Albinism, causing fair skin, eye issues, and golden hair. Despite genetic testing during pregnancy, the condition was not detected until the twins were born.*

The human skin displays a wide range of natural colors and tones that contribute to each individual's unique appearance. However, certain pigmentation disorders can disrupt this balance, resulting in areas of skin that are either lighter or darker than the surrounding skin. These conditions underscore the importance of embracing diversity, practicing self-acceptance, and promoting empowerment.

Introduction

Skin pigmentation disorders are conditions that alter the skin's color. They are a significant dermatological issue for individuals with pigmented skin tones, particularly prevalent among the Indian population. Albinism, Melasma, Vitiligo, and changes in pigmentation due to skin damage are common examples of such disorders.

Melanin, a pigment produced by specialized skin cells called Melanocytes, is responsible for giving skin its color. Destruction of Melanocytes can result in changes in skin color. The impact of these disorders can vary, affecting either a small area of the body or the entire body depending on the underlying cause and progression of the condition.

Melasma, known as the "mask of pregnancy", results in the formation of brown or grey patches on the face, specifically on the cheeks, forehead, nose, and upper lip. ***Piebaldism*** is a genetic condition that leads to depigmented patches of skin and hair since birth. ***Waardenburg Syndrome*** is a genetic disorder that impacts the coloration of hair, eyes, and skin and can lead to hearing impairment. It is triggered by mutations in various genes such as PAX3, MITF, and SOX10, which play a role in the growth and movement of melanocytes during fetal development.

Stigma surrounding Skin Conditions

Misconceptions about these disorders are frequently caused by a ***lack of appropriate information and awareness*** among the general public. Many communities have ***deeply entrenched beauty standards*** that value certain physical characteristics, such as a specific skin colour or homogeneity. Some cultures may link these diseases to harmful beliefs, myths, or superstitions. These cultural ideas can perpetuate stigma, resulting in social exclusion and discrimination. ***Media portrayal*** has a huge impact on public perceptions. Negative or sensationalist portrayals of people with these disorders can add to stigma and promote preconceptions.

These conditions can seriously impact a person's mental health

People living with this disorder are emotionally affected, and in some cases, it has influenced who they have become. Some people encounter discrimination in job searches because of how their skin looks. "A few years ago, I applied for a job in sales at a popular hotel", Ravi recalls. "***I recall one of the senior management staff stating, 'This is a position that works with clients***', and other comments to the effect that they might lose business if I was in the role.

Want to be seen for more than their skin

When interacting with someone who suffers from these disorders, we should be "***empathetic***" and "***kind***". Educating oneself and acknowledging the emotional effect of this condition is tough for people on many levels. Also, one must be helpful and understanding. Let them know they're not alone. The more we discuss and normalize it, the closer we will come to a time when people with these skin diseases may feel completely comfortable and accepted in their own skin, which is something everyone wants and deserves.

Many Birth Defects, One Voice

Introduction

Living with congenital diseases presents unique challenges, both for individuals and their families. Living with congenital diseases poses distinct challenges for both individuals and their families. Approximately 8 million new-borns worldwide are born with congenital disabilities annually, with a higher prevalence in low and middle-income countries. Conditions like autism, genetic disorders, and bleeding disorders can significantly impact a person's life.

Common severe congenital disabilities include heart defects, neural tube defects, and Down Syndrome. Financial obstacles, lack of awareness, and uneven access to care services are key challenges faced by those with congenital disabilities. In South-East Asia, congenital disabilities contribute significantly to child and neonatal mortality rates. Deaths related to congenital disabilities saw a notable increase between 2010 and 2019, with such disabilities accounting for around 22% of global deaths in the Southeast Asia Region in 2019.

The prevalence of congenital defects in India varies depending on the specific type of defect and the region. However, it is estimated that approximately 2-3% of all live births in India are affected by congenital defects. Different parts of the body may be affected by a range of birth defects. Let's take a look at common birth defects that are classified by body system and prevalence.

1 Central nervous system

Neural Tube Defects (NTDs) are common birth defects in India, including spina bifida and anencephaly. The estimated prevalence of NTDs in India is approximately 1-3 cases per 1,000 live births.

4 Gastrointestinal

Oesophageal atresia, a condition in the oesophagus, is believed to affect approximately 1 in 2,500-4,500 live births in India. ***Anorectal malformations,*** which impact the anus and rectum, have a reported prevalence of about 1-2 per 5,000 live births in India.

2 Cardiovascular

CHDs are the most prevalent birth defects worldwide, impacting around 8-10 out of every 1,000 live births in India.

5 Genitourinary

Hypospadias is a commonly seen genital defect in males, characterized by the urethral opening being situated on the underside of the penis. In India, it affects approximately 3-4 out of 1,000 live births. Renal anomalies such as polycystic kidney disease and renal agenesis can impact the kidneys. The prevalence of renal anomalies in India is estimated to be around 2-4 per 1,000 live births.

3 Musculoskeletal

Clubfoot is a frequently occurring birth abnormality in India, affecting around 1-2 out of every 1,000 live births. Cleft lip and palate are facial deformities that develop during foetal growth, with a prevalence of approximately 1-2 per 1,000 live births in India.

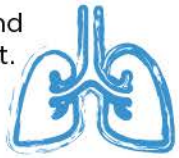
Common Genetic Disorders associated with Birth Defects

1 Down Syndrome (Trisomy 21)

is a chromosomal disorder caused by the presence of an extra copy of chromosome 21. It leads to intellectual disabilities, characteristic facial features, and an increased risk of various health conditions such as heart defects, gastrointestinal abnormalities, and hearing loss.

2 Thalassemia

is a group of inherited blood disorders that affect the production of haemoglobin. Thalassemia major, also known as ***Cooley's Anaemia***, can cause significant birth defects and requires lifelong blood transfusions and medical management.



3 Sickle Cell Disease

is an inherited blood disorder characterized by abnormal haemoglobin, leading to misshapen red blood cells. The condition can cause episodes of pain, organ damage, and other complications.

4 Muscular Dystrophy

refers to a group of genetic disorders characterized by progressive muscle weakness and degeneration. ***Duchenne Muscular Dystrophy*** can lead to significant physical disability and birth defects related to muscle function.

5 Cystic Fibrosis

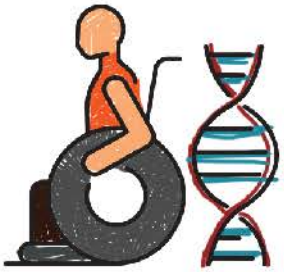
is an inherited disorder that affects the lungs, digestive system, and other organs. It causes the production of thick, sticky mucus that can lead to breathing difficulties, digestive problems, and other complications.

6 Fragile X Syndrome

is a genetic disorder characterized by intellectual disabilities and behavioural challenges. It is caused by a mutation in the ***FMR1 gene*** and can be associated with physical characteristics and developmental delays.

7 Neurofibromatosis

is a genetic disorder that causes tumours to develop on nerve tissue. It can result in various birth defects, including skin abnormalities, bone deformities, and neurological complications.



W.H.O efforts & raising the common voice

Since 2014, W.H.O has been helping countries reduce maternal, newborn, & child mortality by focusing on preventing birth defects through measures like vaccinating against rubella & providing folic acid supplements. Access to advanced treatments is limited, so there is a need to enhance health systems and focus on prevention.

The human voice advocates for empowerment, inclusion, & access to crucial services like healthcare and education, promoting self-empowerment & building supportive communities for those with congenital conditions. Research, innovation, and systemic changes are encouraged to address discrimination and inequality, while celebrating the resilience and contributions of individuals with congenital diseases.

Embracing diversity and advocating for change can bring growth, connection, and happiness to those affected by these conditions, inspiring us to value and support everyone regardless of their medical challenges.

India's Children & Grim Reality of Congenital Heart Diseases

Introduction

Congenital heart disease (CHD) affects 1 in 100 children globally, with survival rates depending on access to early treatment. In India, over 90% of children lack advanced care for CHD, leading to higher child mortality rates. The World Health Organization estimates that 8 out of 1000 live births are affected by CHD, with India seeing around 180,000 CHD cases each year, of which 60,000 to 90,000 are critical. Sadly, 98% of critical cases result in infant mortality, making up 10% of all infant deaths. India diagnoses around 100,000 CHD cases annually, but only 8,000 to 9,000 are accommodated by healthcare facilities.

What are congenital heart defects?

Congenital heart defects are structural abnormalities that affect heart function, often developing in early pregnancy. These defects can vary in severity, with some requiring immediate medical intervention. Around a quarter of cases are critical, leading to inadequate oxygenation of blood and cyanosis. Surgery is necessary within the first year of life for critical defects. Advances in diagnosis and treatment have improved outcomes for individuals with complex heart defects, allowing them to live full lives into adulthood.

8 of the most common types of Congenital Heart Defects

1 Ventricular Septal Defect (VSD)

is a condition where there is an opening in the wall between the two lower chambers of the heart, potentially leading to increased pressure in the heart or decreased oxygen to the body.

2 Atrial Septal Defect (ASD

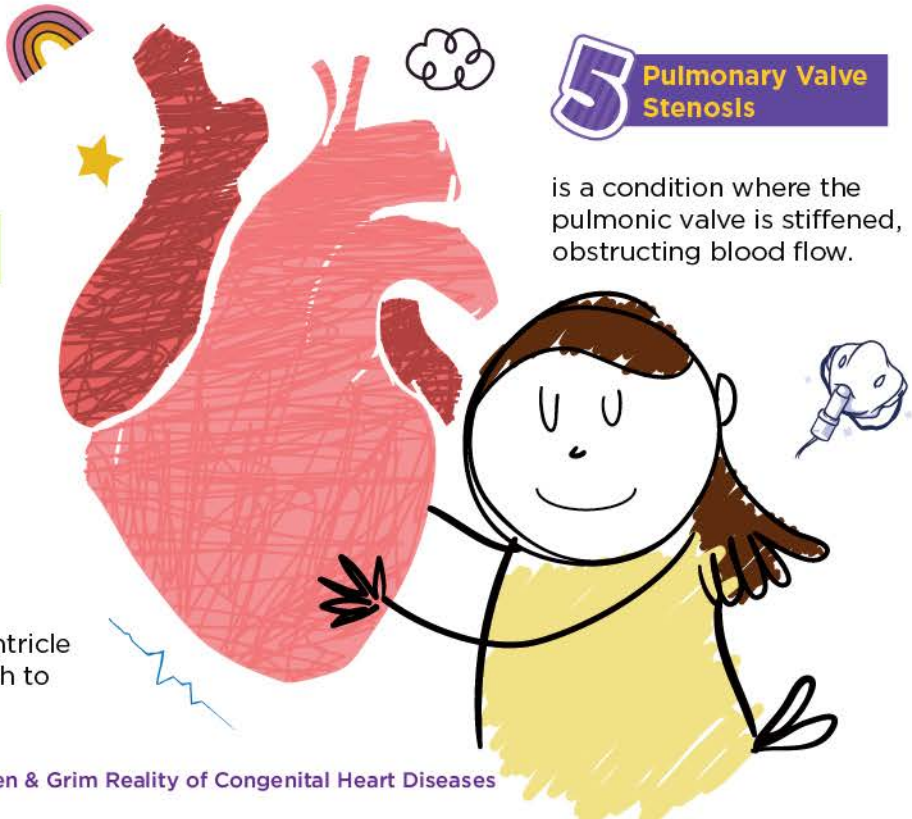
involves a hole in the atrial septum, the wall separating the heart's two upper chambers of the heart.

3 Single Ventricle Defect

is when a child is born with a heart that has only one ventricle that is large or strong enough to pump effectively.

4 Tetralogy of Fallot (TOF)

is a combination of four heart defects that affect infants and children, altering the flow of blood through the heart and lungs.



5 Pulmonary Valve Stenosis

is a condition where the pulmonic valve is stiffened, obstructing blood flow.

6 Patent Ductus Arteriosus (PDA)

is a persistent opening between two major blood vessels.

7 Aortic Valve Stenosis

is a heart valve disease that reduces or blocks blood flow from the heart to the aorta and the body.

8 Dextro-Transposition of the Great Arteries

is a serious heart defect where the two main arteries in the heart are switched, causing blood to be carried to the wrong location.

What are the causes & symptoms of Congenital Heart defects?

Heart defects can result from a combination of genetic factors such as chromosomal abnormalities and single gene defects, as well as environmental influences.

If a mother has a congenital heart defect, there is a possibility that her child may inherit it genetically. Conditions like ***Down Syndrome and DiGeorge Syndrome*** are associated with approximately 15% of all heart defects. Genetic testing can assist in assessing the likelihood of a subsequent child developing the same condition if an older child has a heart defect.

Congenital heart defects are typically identified shortly after birth or within the first few months, with symptoms including bluish skin or lips (Cyanosis), rapid breathing, swelling, and feeding difficulties leading to slow weight gain.

How parents play a crucial role?

Parents should make an effort to learn about their child's heart condition, treatment options, and available resources to be ***well-informed*** and advocate effectively. ***Participating*** in support groups can provide ***emotional support*** & helpful advice. It is important to ***promote regular exercise*** and a ***healthy diet*** for the child's overall health.

Keeping a close eye on ***developmental milestones*** and seeking early intervention can ***lead to better*** outcomes. In India, parents should take the ***initiative to access specialized*** healthcare services for children with congenital heart defects.

What lies ahead?

Training programs for pediatricians are now focusing on detecting critical heart defects in newborns, providing immediate care, and making appropriate referrals. Government insurance programs such as ***RBSK*** and ***PMJAY*** cover heart defects for vulnerable populations, while NGOs offer financial assistance for surgeries.

State-specific schemes like ***Bal Hriday Suraksha Yojana*** provide funding for pediatric cardiac care. More awareness campaigns are needed in semi-urban and rural areas to educate the public on the seriousness of heart defects and the importance of early detection and treatment.

Collaboration with healthcare professionals is essential for improving care for children with CHD, and proposed solutions should consider the social, economic, and political structures of the region. Advocacy with policymakers is crucial for effective resource allocation, and research should align with local needs to support these initiatives.

Navigating to New Life of Parenthood

The importance of premarital screening and counselling

When starting a family, it's crucial to be aware of genetic factors that can increase the chances of congenital disabilities. These conditions, present at birth, can impact a child's physical or mental well-being and may result from genetic or environmental causes. While not all congenital disabilities can be prevented, taking proactive measures like premarital care and genetic counselling can greatly lower the risk and improve children's health outcomes. Premarital care involves health assessments and screenings before marriage or conception to identify potential health risks, including genetic disorders, in both partners. By conducting a thorough evaluation, couples can make informed decisions and take necessary precautions to reduce the likelihood of passing on genetic disorders to their offspring.

Below are common genetic disorders that can be screened:

1 Cystic Fibrosis

is a genetic disorder that impacts the lungs, digestive system, and other organs. Genetic testing can pinpoint carriers of the CF gene mutation, enabling couples to evaluate the likelihood of transmitting the condition to their offspring.

2 Sickle Cell Disease

is an inherited blood disorder characterized by abnormal haemoglobin production. Genetic counselling and testing can ascertain if both partners carry the sickle cell trait, which heightens the chances of having a child with the disease.

3 Tay-Sachs Disease

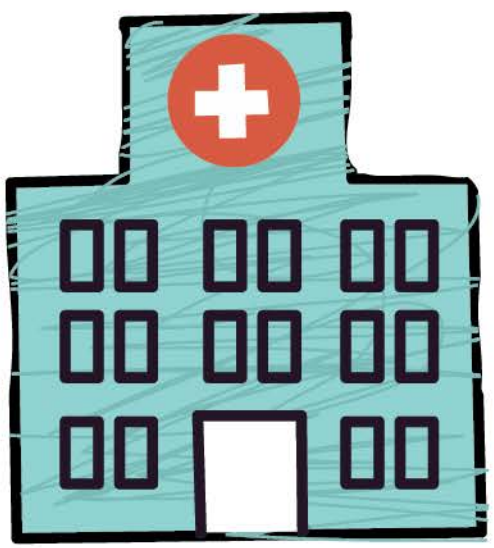
is a rare and deadly genetic disorder affecting the nervous system. Genetic screening can pinpoint carriers of the Tay-Sachs gene mutation, enabling couples to make informed choices regarding family planning.

4 Haemophilia

is a genetic disorder that hinders the body's ability to clot blood, leading to prolonged bleeding and an increased risk of bleeding episodes. Genetic counselling can help identify families with a history of haemophilia and offer information on the likelihood of passing on the condition to future generations.

5 Down Syndrome

is a chromosomal disorder caused by an extra copy of chromosome 21. Prenatal screening tests such as non-invasive prenatal testing (NIPT) or prenatal genetic counselling can help detect the risk of Down Syndrome in the developing fetus.



6 Thalassemia

is an inherited blood disorder (passed from parents to children through genes) caused when the body doesn't make enough of a protein called hemoglobin, an important part of red blood cells. Symptoms include fatigue, weakness, paleness, and slow growth. Testing should be done with people with a family history or a spouse/partner should be tested in case one has already been diagnosed as a thalassemia carrier.

It is important to consider that the types of genetic disorders included in screenings may vary based on factors like ethnicity, family medical history, and the prevalence of certain conditions in a particular area. Through genetic testing and counseling, individual risk factors can be identified and the screening process can be personalized accordingly.

The role of genetic counselling

Genetic counselors ***evaluate*** the ***medical histories*** of both individuals to identify inherited disorders and provide information on ***preventative measures.*** They inform couples about the ***potential risks*** of certain genetic conditions, allowing them to make ***well-informed decisions*** regarding ***family planning.*** Counselors also help high-risk couples with ***prenatal screening,*** offering support and resources for ***coping with congenital disabilities.***

Reducing the risk of birth defects

Premarital care and genetic counseling ***are essential for identifying*** genetic risks before conceiving, ***allowing couples*** to reduce the chances of passing on disorders. With ***personalized guidance,*** couples can make informed decisions about family planning to minimize risks and ensure optimal choices for their future family. By addressing genetic ***risks early on, healthier generations can be promoted through improved*** health outcomes for children.

Start your lifelong journey right!

Pre-marital health screening is beneficial in promoting transparency, preventing disease transmission, and ensuring the well-being of couples and their potential children. It allows individuals to address any health concerns, make informed decisions about their reproductive health, take necessary precautions, and seek medical advice. This proactive approach increases the likelihood of a healthy pregnancy and encourages open communication and shared responsibility in managing chronic illnesses.

Understanding Health Insurance Coverage for Congenital Diseases in India

Maintaining good health through a well-rounded lifestyle of proper nutrition, sufficient rest, and consistent exercise is an effective way to avoid illness. However, individuals with congenital conditions may not have the same opportunity to prevent health issues. In India, the extent of coverage for congenital diseases can differ among health insurance policies. This brings up the question of whether health insurance plans in India offer protection for congenital diseases. Let's delve deeper into this subject.

What are Congenital Diseases?

A congenital disease or disorder is a medical condition that a person may have from birth, either inherited or caused by environmental factors. A joint report by the World Health Organization (W.H.O) and March of Dimes (M.O.D) in 2016 found that over 1.7 million people in India have congenital diseases, which is approximately 6 to 7% of the population.

These disorders typically originate during pregnancy and can be detected before, at, or after childbirth. While the medical effects of these disorders are not always severe, in some cases they can have serious consequences. Internal congenital disorders are usually not easily visible, while external disorders may be more easily identifiable.

Common types of Congenital Diseases

Some of the most common types of congenital diseases are as follows:

1. **Down Syndrome**
2. **Congenital Heart Disease**
3. **Cleft Lip and Cleft Palate**
4. **Cerebral Palsy**
5. **Spina Bifida**
6. **Club Foot**
7. **Edward's Syndrome**
8. **Thalassemia**
9. **Phenylketonuria**
10. **Fragile X Syndrome**
11. **Cystic Fibrosis**
12. **Sickle Cell Disorder**
13. **Congenital Hypothyroidism**

Do health insurance plans cover congenital diseases in India?

According to the 2019 guidelines from IRDAI, all standard health insurance plans in India provide coverage for congenital diseases. These plans include coverage for diagnosing and treating congenital diseases, such as in-patient hospitalization, daycare procedures, surgeries, pre-hospitalization, post-hospitalization, and more.

The Master Circular on Standardisation in Health Insurance Business, dated 29th May 2024, ensures newborns with internal congenital disabilities receive coverage from birth. However, it depends on the policy coverage one is opting for.

The coverage amount can range from Rs 50,000 to Rs 6 crore, depending on the specific health insurance plan purchased.

It is important to note that not all congenital diseases are covered by health insurance plans in India. Only internal congenital diseases are eligible for coverage, while external congenital diseases are not covered.

Waiting period for congenital diseases under health insurance

Health insurance providers usually cover Congenital Diseases, but it's important to understand that there may be a waiting period before you can file a claim for such a condition. Most health insurance plans have a two-year waiting period for coverage of congenital conditions, meaning you can only submit a claim after two policy cycles. This rule applies if the diagnosis is made after you buy the policy. However, if the diagnosis was made before purchasing the policy, the disease may be considered a pre-existing condition, and you may have to wait up to four policy cycles before being eligible for coverage. Be sure to carefully review your health insurance plan's policy terms and conditions for more details on the waiting period clause.

Things to consider before buying a policy

1 Waiting Period

The duration of coverage for congenital conditions can vary from 2 to 4 years, during which the policyholder may not be able to claim related expenses.

2 Pre-existing Conditions Exclusions

Pre-existing conditions refer to medical conditions existing before obtaining health insurance, which some insurers may not cover initially but could be included after a waiting period.

3 Policy-Specific Exclusions

Some policies may exclude specific conditions such as genetic disorders or long-term care needs. It is important to carefully review policy documents to understand these exclusions.

4 Sub-limits & Caps

Certain policies may have limits on coverage for congenital conditions, requiring the policyholder to pay for a portion of the expenses.

5 Hospital Network

Consider choosing an insurer with a wide network of hospitals and healthcare providers specializing in congenital diseases for more treatment options.

6 Renewability

Look for policies that offer lifelong renewability without coverage restrictions for congenital diseases to ensure continued protection as the insured individual ages.

7 Additionally, explore any extra benefits or optional riders provided by insurers.

Summing it up!

Health insurance for congenital diseases in India has certain conditions, waiting periods, and exclusions that need to be carefully reviewed in policy documents. It is important to have comprehensive coverage to address these conditions due to the increasing prevalence of congenital diseases. This will help ensure financial stability and access to quality healthcare for individuals and families.

Revisiting Autism:

Learning to Sensitize Family and Caregivers to Support Children with Special Needs

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Consultant Developmental Pediatrician
[MBBS, MD (Pediatrics), CCT]
Rainbow Children's Hospital, Hyderabad

"It takes a village to raise the child".

The world of child development is witnessing an unusual phenomenon with a steady rise in the number of children diagnosed with Autism Spectrum Disorder (ASD). The Centres for Disease Control and Prevention (CDC) has indicated a prevalence rate of 1 in 36 children in the US. While the exact prevalence figure is not known in India, it is estimated to be close to 1 in 100, which is significant. While the rising number of cases is concerning, what is more worrying is the lack of understanding of what causes autism and why this is happening. Even more challenging is the fact that there is no confirmatory laboratory test available, and to date, there is no known cure for this condition.

The cause of autism remains unknown, but there is a growing suspicion that environmental factors may play a role. Certain demographic factors, such as working parents, nuclear families, and early exposure to screen time, may contribute to autism. Urban populations have higher rates of autism than rural populations. The country is experiencing urbanization, increasing employment opportunities, and migration. The modern nuclear family raises children differently than traditional practices, with children spending more time on screens than interacting with humans. This altered ecosystem may impact child development. The perceived rise in developmental problems in children during the pandemic further strengthens the view of environmental influences and offers some insights into the association with autism.

Despite the lack of a cure for autism, early intervention has shown promising results and is currently the mainstay of treatment. While parents may be confused by the many different treatments being promoted, there is evidence to support the effectiveness of interventions such as sensory integration, prelinguistic skill and communication development, behaviour therapy, and learning skills. By focusing on these interventions, parents and healthcare providers can help improve outcomes for children with autism.

It's important to know that there are alternative treatments available for Autism Spectrum Disorder (ASD), such as nutritional supplements, dietary treatments, and hyperbaric oxygen therapy. However, it's crucial to note that these treatments lack solid evidence. Earlier this year, the National Medical Commission banned the use of stem cell therapy for the treatment of ASD. Some state-led institutions and NGOs offer therapy at nominal costs, but they are not enough to meet the growing demand. Unfortunately, insurance coverage for these treatments is mostly non-existent, and parents end up investing large amounts of money in treatments, risking running out of funds.

Parents often ask if their child can lead a ***"normal life"***. Being a spectrum disorder the severity of ASD varies from one individual to another. Some thrive well and in fact, can be exceptionally able in their field of interest. Children with impaired language and cognition are more likely to face challenges with education, employment, relationships, and independent living.

How can parents reduce the risk?

Engage grandparents/relatives to talk to the child. Speak to the baby often with emotions, and expose them to 10,000 spoken words daily. Avoid gadgets before 3 years of age, and limit high sugar intake. Involve the community in raising the child.

With increasing urbanization and the breakup of the larger family structure and lack of social security it falls on the parent to take care of children with autism. With a rising population of children on the spectrum, social support infrastructure and parental support are what can help these special children. We will need to look at measures to protect the ***"first thousand days"*** of a child's life such as promoting early mother-child bonding, parentcraft, the importance of human connections and community, and the need to educate parents and families about the importance of first thousand days. Antenatal care may be an opportunistic time to engage with parents.

As we stand on an important threshold where human development is based purely on GDP and numbers, it is important to understand and correct the factors that adversely affect children's development. Children are our most important human resource and it is vital that as a society we protect this phase of human development, through research, promotion of human connection, and drawing from traditional ways of child-rearing with multigenerational families.

Parenting Children with Disabilities:

Where Love knows NO Bounds & Strength knows NO Limits

Dr. David Suvarna Raju Parimi
Consultant Pediatrician, Rainbow Hospitals, Kondapur, Hyderabad

Children with disabilities are a diverse group of individuals who encounter unique difficulties and challenges in their daily lives. ***According to a UNESCO report from 2019, nearly 240 million children worldwide and 78.64 lakh children in India have some type of disability.*** Despite these challenges, they demonstrate remarkable resilience and determination. Parenting is a rewarding journey with its share of joys, difficulties, and surprises. The parents of children with special needs exhibit extraordinary levels of love, commitment, and resilience, setting an example for us all. Their experiences, successes, and coping mechanisms inspire us to face challenges head-on and appreciate the beauty in every moment.

Children with special needs require extra care and attention, and as parents, we want the best for our children, including those with special needs. However, the journey of raising a special needs child is not without its challenges. The label of disability can make the child feel different from others, and this can affect not only the child but also the parents and siblings. It is difficult for parents to come to terms with this reality. When parents learn that their child has a disability, it can be overwhelming and emotional. It is common for parents to feel a sense of grief and loss for the dreams and expectations they have for their children.

Parents may experience a wide range of negative feelings, such as rejection, guilt, blame, frustration, anger, and despair. Parents need to know that these feelings are valid and normal. It is crucial to seek support from other parents, family members, and professionals who can help guide them through this process. Parents should try to focus on their child's unique abilities and strengths, and celebrate their accomplishments, no matter how small they may be.

Parents must know the right approach when dealing with this. Let's understand how parents can cope with this most effectively:

1 Redefining Normalcy

Parenting a child with special needs often involves navigating uncharted territory. It requires embracing a new definition of normalcy and celebrating the milestones, big and small, that come along the way. By recognizing and accepting the uniqueness of their child, parents can create an environment that fosters growth and self-acceptance.

2 Embracing the Journey

The journey of parenting a child with special needs is marked by various emotions, from joy and gratitude to frustration and worry. Parents need to acknowledge and embrace these emotions, seeking support from communities, support groups, and professionals who can provide guidance and understanding. Remember, you are not alone on this path.

3 Empowering Advocacy

Advocacy plays a crucial role in ensuring that children with special needs receive the care, resources, and opportunities they deserve. Parents are the most powerful advocates for their children, championing their rights, and breaking down barriers. By amplifying their voices, parents can create positive change and promote inclusivity in society.

4 Cultivating Self-Care

Parenting a child with special needs can be demanding, both physically and emotionally. Parents need to prioritize self-care and seek respite when needed. Taking time for oneself helps maintain a healthy balance and equips parents to provide the best possible care for their child. Remember, self-care is not selfish; it is a necessity.

5 Celebrating Triumphs

Every achievement, no matter how small, is cause for celebration.
Whether it's a first step, a new word, or a breakthrough in therapy, recognizing and commemorating these triumphs bolsters both the child's and the parent's spirits.
By focusing on strengths and accomplishments, parents can inspire their children to reach for the stars.

6 Fostering Inclusion

In a world that often struggles to understand and accommodate differences, parents of children with special needs play a vital role in fostering inclusivity.
By educating others, promoting acceptance, and advocating for inclusive practices, parents can help create a more compassionate and understanding society for their children and future generations.

Parenting children with special needs is an extraordinary journey that requires unwavering love, patience, and resilience. It is a journey filled with unique challenges and remarkable triumphs. By embracing the extraordinary, advocating for their children, and nurturing their limitless potential, parents can create a world where every child, regardless of their abilities, can thrive.

What do you Need to Know About Inclusion in Education?

Inclusive education is a fundamental right that provides equal educational opportunities for people with various disabilities, including congenital disorders. These conditions are present at birth and can affect physical, cognitive, or sensory functions. It is crucial to recognize the advantages of inclusion in education for those with congenital disorders and implement strategies to create an inclusive learning environment. UNICEF reports that globally there are around 240 million disabled children, with one in ten lacking access to essential aspects of child well-being. These children are at higher risk of unhappiness, never attending school, and facing discrimination. Unhappiness, never attending school, and facing discrimination.

Disability is not homogenous

To be inclusive, the education system should cater to the diverse needs of learners with disabilities such as autism, blindness, deafness, and intellectual disabilities.
A personalized approach is necessary as a one-size-fits-all method is ineffective.
Research shows that incorporating different learning techniques like repetition, personalized pacing, visual aids, and simplified language benefits all students. By focusing on specific disabilities, the education system can improve overall outcomes.

Inclusive education in India: A historical perspective

The number of schools for children with special needs in India has been increasing over the years, as reported by the Indian Disability Status 2003. The first school for the deaf was established in Mazagaon by a Roman Catholic Mission in 1884, followed by the Calcutta Badhira-Muka Vidyalaya in 1893 and a school in Palayamkota in 1896. Currently, there are over 2000 special schools in India, but many children in rural areas are still not being catered to.

In the history of Indian inclusive education, the Kothari Commission in 1966 emphasized educating children with disabilities in regular schools. The Government of India's Integrated Education for Handicapped Children (IEDC) program was launched in 1974 to promote inclusion. This scheme, sponsored by the central government, aims to provide educational opportunities for children with special needs in regular schools. Inclusive Education has been a significant part of the Sarva Shiksha Abhiyan (SSA) RTE and Rashtriya Madhyamik Shiksha Abhiyan (RMSA) schemes, offering support such as aids, appliances, corrective surgeries, braille books, and therapeutic services.

Value of Inclusive education

1 Embracing Diversity:

Inclusive education promotes diversity among students, regardless of their abilities or health conditions, to foster a supportive learning environment.

2 Equal access to Education:

It aims to eliminate obstacles to participation by offering tailored support and assistive technologies for individuals with congenital diseases.

3 Improved social inclusion & promoting self-advocacy:

Encouraging social integration helps build relationships and challenge stereotypes, empowering individuals to advocate for themselves and acquire skills for future success.

Strategies for Promoting Inclusive Education in India

1 Inclusive Policy & Legal Framework

In line with the legal framework laid down by the Rights of Persons with Disabilities Act of 2016, schools and institutes should develop inclusive policies. Equal opportunities, non-discrimination and appropriate accommodation of persons with disabilities are enshrined in the legislation.

2 Conduct Sensitisation Programmes

and training for teachers, administrators and support staff. Awareness of disability, understanding different disabilities, inclusive teaching methods and strategies for accommodating diverse learning needs should be addressed in these workshops.

3 Individualized Education Programs (IEPs)

are personalized plans that set goals and provide necessary support for students with unique needs. Regularly reviewing and monitoring IEPs is crucial for addressing students' progress and changing needs effectively.

4 Accessibility & Infrastructure

Providing a variety of assistive technologies and resources is essential to meet the diverse needs of students with disabilities. Augmentative and alternative communication devices, screen readers, adaptive computer input devices, and accessible learning materials are important tools for children with disabilities.

5 Assistive Technologies

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6 Special Educators

who are trained to work with these children can offer specialized instruction and collaborate with mainstream teachers for inclusive practices.

7 Collaboration

The collaboration of schools, parents, and disability organizations is crucial for providing comprehensive support and promoting the well-being and educational progress of children with disabilities in inclusive educational settings.

Conclusion

To effectively implement an inclusive education system in India, it is essential to educate parents, teachers, and all children, including those without disabilities, about the system and its advantages. These individuals are crucial in the implementation process as they regularly interact with children with disabilities and are part of their immediate environment. It is important that children with disabilities have the same access to inclusive and high-quality education as their peers in the communities where they reside.

Advancements in Studying Cellular Signalling Pathways in Inherited Retinal Degenerative Diseases

Introduction

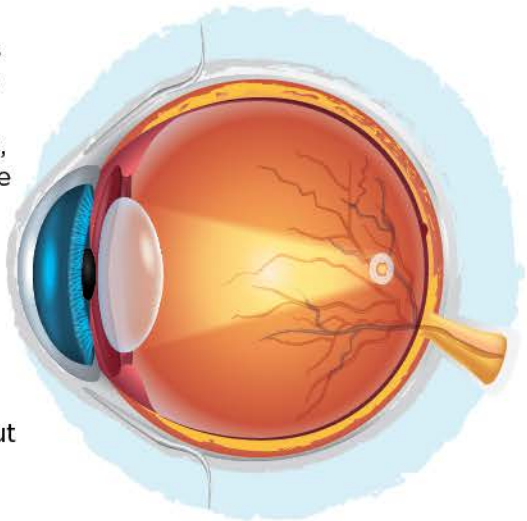
Sight is often considered the most important of the five human senses, as it is the main way humans gather information. Early research on perception and memory focused heavily on vision. The retina, a complex structure in the eye, converts light into electrical signals that are then processed by the brain. Losing vision can be a frightening experience for many, with up to 75% of people reporting fear of vision loss. Inherited retinal diseases are a major factor in vision loss, affecting millions of people worldwide. These conditions can lead to severe vision impairment, particularly in children, and can have significant impact on families and communities.

What are IRDs?

Inherited Retinal Diseases (IRDs) are a collection of hereditary disorders that impact photoreceptor cells in the retina, leading to significant vision loss or blindness. Each IRD is linked to at least one malfunctioning gene. These diseases can affect individuals of all ages, progress at different speeds, and are not common. IRDs target various retinal cells, including Retinitis Pigmentosa (RP), Usher Syndrome (USH), Rod Dystrophy, Batten disease, Bardet-Biedl Syndrome (BBS), Alport Syndrome, Achromatopsia, Congenital Stationary Night Blindness (CSNB), Macula Dystrophy, among others.

What causes IRDs?

An IRD is a genetic condition resulting from a mutation in a gene essential for retinal function. This disease impairs the gene's ability to perform its functions effectively, leading to vision loss. Over 270 distinct genes are known to cause IRDs, with some more severe than the others. Identifying the precise type of gene mutation help doctors provide accurate diagnosis and refer patients to clinical trials for potentially saving their vision. Genetic testing can now identify most IRD-causing gene variations, but not all.



Recent technological advancements

In recent years, technical developments have transformed the study of cellular signaling networks, giving researchers crucial tools for unravelling the complexity of hereditary retinal degenerative illnesses.

The revolutionary ***CRISPR-Cas9 Gene Editing System*** has transformed the field of genetics and holds enormous promise for inherited retinal degenerative diseases. Researchers can use CRISPR-Cas9 to precisely modify genes associated with these diseases, allowing them to investigate the functional consequences of specific gene mutations. This technology enables the creation of cell and animal models that closely mimic the disease conditions, providing a platform for studying cellular signalling pathways and testing potential therapeutic interventions.

Traditional two-dimensional cell cultures often fail to faithfully summarize the complexity of human tissues. ***Organoids*** are self-organizing, three-dimensional structures that resemble specific organs, including the retina. Researchers can generate retinal organoids from patient-derived induced pluripotent stem cells (iPSCs) and study the cellular signalling pathways in a more physiologically relevant context. These ***3D Culture Systems*** offer a powerful platform for drug screening, personalized medicine, and understanding disease progression.

Advancements in ***Imaging Technologies*** have played a crucial role in visualizing cellular signalling pathways and molecular processes in inherited retinal degenerative diseases. Techniques such as ***Confocal Microscopy, Super-Resolution Microscopy,*** and live-cell imaging provide high-resolution visualization of cellular structures and dynamic processes in real time. These imaging tools allow researchers to observe the interactions between different molecules and signalling components, providing valuable insights into disease mechanisms.

Conclusion

Technological developments have greatly improved our understanding of cellular signaling mechanisms in hereditary retinal degenerative disorders. These findings offer considerable promise for unraveling the complexity of retinal degeneration and paving the door for novel treatments to restore or preserve vision in affected individuals. Continued development in these areas will surely get us closer to curing inherited retinal degenerative illnesses and enhancing the quality of life for millions of individuals around the world.

Embracing Abilities: Celebrating the Triumphs

Zainika Jagasia is a Down Syndrome model, influencer, and baker who isn't afraid of challenges. Despite facing obstacles, Zainika's positive attitude and determination have helped her achieve her dreams. In this interview, Zainika talks about her supportive family and her goals for the future.

1 Tell us about your family.

It's 4 of us. Me, my sister & parents. They're all super loving & supportive.

2 What do you appreciate most about your family?

My mom never gives up on me, she has always pushed me to work harder. She's been the driving force during my childhood. My dad is the most loving and non-judgemental person. My sister believes in me and trusts me to achieve whatever I desire.

3 Can you tell us about your diagnosis?

I was diagnosed with Down Syndrome at birth, a condition wherein an individual is born with an extra chromosome which causes developmental delays.

4 How has your diagnosis impacted your life?

It hasn't. I have worked harder than anyone else and now I get to reap the benefits. Just like everyone else, I go to work, I work out, and enjoy life as everyone does.

5 How do you manage challenging and tough days?

Positivity. At first, of course, I want to cry or sulk but then I pick myself up by motivating myself that I can get through it, anything is possible.

6 What are your goals and aspirations? What concerns do you have regarding the future?

A few years ago I didn't know what I wanted to be and I kept switching my mind about wanting to be a singer, dancer, or policewoman (blame TV shows). But now I have clear aspirations, I want to model for Gucci and other major fashion houses, and grow my business, a cookie brand.
I am a baker & I run the brand along with my sister. I've also launched my cookie line "Zain's Mini Cookies".
I wouldn't say I have concerns but I definitely have goals and dreams that I want to achieve, so sometimes I wonder when that'll happen which comes down to having patience.

7 How do you rejuvenate yourself? What activities do you enjoy during your personal time?

I absolutely love dancing. I've been taking dance classes for years. I also enjoy going for my Bootcamp, Sohfit. Music is my other passion.

8 What advice would you give to other people who have a loved one who has received a diagnosis similar to yours?

Just believe in them. There are days you'll want to give up but please don't. Just be patient and give them the love & support they deserve.

9 What would you like people to know about you?

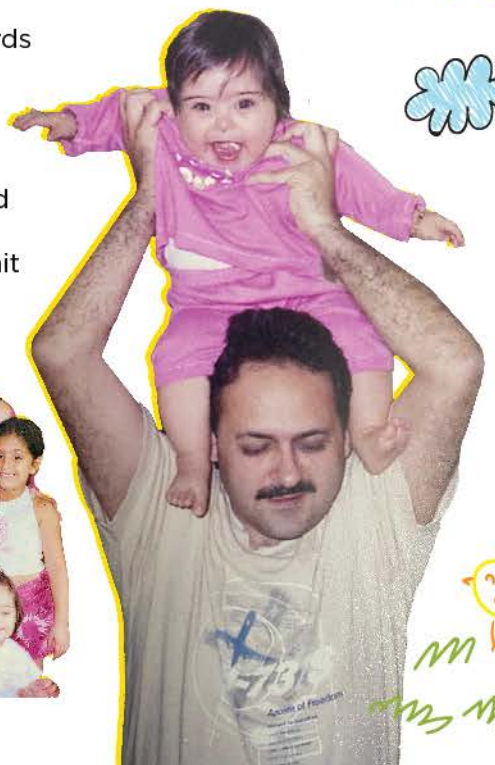
I am a powerhouse. I don't think there's anything I can't achieve once I've set my mind to it. I am really the most hard-working & diligent person you'll come across and the best part is, I always do it with a smile on my face. I am also forgiving, it's not in my nature to be mad at someone for long.

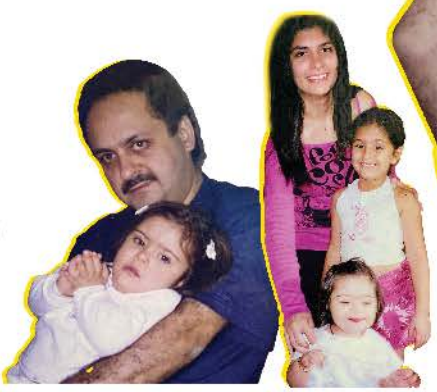
10 Who is your role model, someone who has inspired you?

My sister, Gitika, is my inspiration. She has always inspired me and made me dream big. She has pushed me to work hard and be independent. Confidence shines through, and she's a perfect example of that. She is the one who has always pushed me towards positive thinking. Positivity always comes when you have hope so when you have hopes and dreams your job becomes to achieve them.

Zainika's journey is a testament to the power of perseverance and positivity. Despite facing challenges, she has blossomed into a successful influencer and model with a bright future. We can't wait to see what Zainika achieves next.

MY FAMILY





Leading the Way:

Countries Championing Support for Intellectual Disabilities

Intellectual disabilities impact a large number of individuals globally, posing distinct challenges that necessitate tailored care and support services. Thankfully, a number of countries have emerged as frontrunners in offering extensive and inventive support for those with intellectual disabilities. Let's highlight the countries that are leading the way in this regard.

What is an intellectual disability?

An intellectual disability encompasses various conditions that result in difficulty in learning, understanding, and processing complex information. Those affected may struggle to acquire new skills or require extra time and support to do so. Individuals with intellectual disabilities often face challenges in daily life and may feel alienated within their society or community. Typically, a person with an intellectual disability will have an IQ below 70 and exhibit significant limitations in multiple skill areas.

Countries that are succeeding in providing support for individuals with special educational needs

1 Norway

is known for its efforts in promoting inclusivity for individuals with intellectual disabilities, ensuring they have access to mainstream schools and vocational training programs.

2 The Netherlands

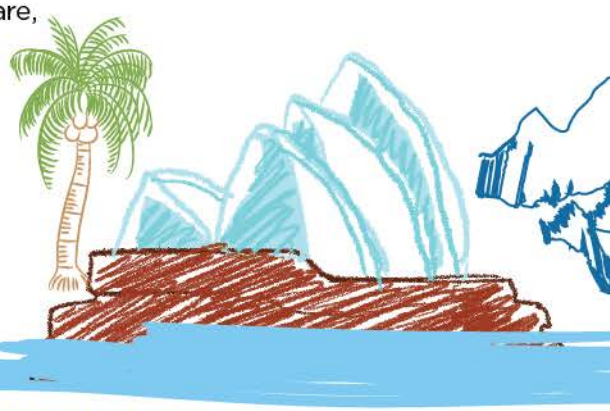
on the other hand, is recognized for its level terrain and hospitable inhabitants. The Netherlands is proactive in supporting these individuals, with a focus on transitioning them from institutions to supported living arrangements.

3 Australia

has made significant progress in adopting person-centred approaches to support individals with intellectual disabilities. ***The National Disability Insurance Scheme (NDIS)*** in Australia is a pioneering program that offers personalized support plans for individuals with intellectual disabilities. This approach prioritizes individual control over support services, emphasizing the importance of choice and autonomy for people with intellectual disabilities. By empowering individuals to participate in decision-making processes related to their care, & their overall quality of life is improved.

4 Finland

has become a global leader in utilizing assistive technologies to empower individuals with intellectual disabilities. Through a dedication to innovation, Finland has developed advanced technologies like augmented communication devices and cognitive support tools. These assistive technologies help individuals with intellectual disabilities improve their communication skills, enhance daily activities, and pursue education and employment opportunities.



5 Canada

is recognized for its acceptance and stunning landscapes. Approximately 0.49 per cent of Canadian adults have an intellectual disability. It's known for its wide-ranging support systems for individuals with intellectual disabilities, which include legislative measures like the Canadian Charter of Rights and Freedoms. The country also offers a variety of community-based organizations and services that provide housing, employment, and recreational programs aimed at promoting social integration and independence.

6 The United Kingdom

in contrast, has implemented measures to support individuals with intellectual disabilities, such as the Access to Work program. This initiative provides financial aid and assistance to those looking for employment. The UK also encourages inclusive workplaces by offering training and resources to employers to help accommodate employees with disabilities, creating an environment where all individuals can thrive.

7 Denmark

is connected to Sweden by the Öresund Bridge & is known for its dedication to supporting all residents, including those with intellectual disabilities. Denmark has been a leader in promoting the ***'normalization principle',*** which emphasizes equal rights for individuals with learning difficulties in terms of living, working, and community participation.

8 India

is making significant efforts to support and empower individuals with intellectual disabilities by promoting their rights and ensuring their active participation in society. ***The Rights of Persons with Disabilities Act (RPWD Act) 2016*** recognizes their rights to education, healthcare, employment, and accessibility. The government's ***Sarva Shiksha Abhiyan (SSA)*** program focuses on inclusive education by providing support services, specialized educators, and assistive devices to help children with intellectual disabilities integrate into regular classrooms. ***The National Institute for the Empowerment of Persons with Intellectual Disabilities (NIEPID)*** offers assessment, diagnosis, therapeutic interventions, vocational training, and rehabilitation programs. Various government and non-governmental organizations provide vocational training programs, such as the ***National Skill Development Corporation (NSDC),*** to equip individuals with disabilities with marketable skills and enhance their employability and independence. Organizations like the ***National Association for the Blind (NAB), Ability Foundation, and Asha Kiran*** play a key role in raising awareness and advocating for the rights of individuals with intellectual disabilities.

Conclusion

The countries listed have shown impressive efforts in assisting individuals with intellectual disabilities through a variety of means such as comprehensive strategies, advanced technologies, inclusive education, and individual-focused programs. These efforts have made a positive impact on many lives and have raised the bar in the field.

Testimonials

As an avid reader of R HealthBeat Magazine, I have consistently been impressed by the depth of research and the clarity with which complex health issues are presented in your articles. Moreover, your magazine plays a vital role in empowering readers to make informed decisions about their health and well-being. By delivering reliable information in a digestible way, you are promoting health literacy and contributing to improved health outcomes in communities. I look forward to reading and learning from your articles in the future.

Mr. Abhishek Jhamb
Infina Insurance Broking Pvt. Ltd
Director

R HealthBeat serves as a valuable health guide, helping me make positive changes to my lifestyle. It simplifies complex information, making it easier for me to understand and implement. This resource has had a positive impact on my overall well-being.

Mr. Pratap Stumpum
AIG Hospitals
Insurance & Corporate Relations

I wanted to thank you for the informative "R HealthBeat" quarterly guide. Your dedication in creating engaging content is commendable. The resource has provided valuable insights and tips, keeping me informed with relevant information. I eagerly await each new edition.

Mr. Rajneesh Tomar
J. K. Cement
Sr. GM Group Insurance

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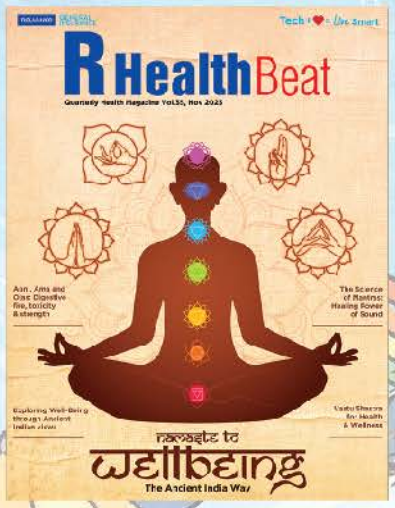

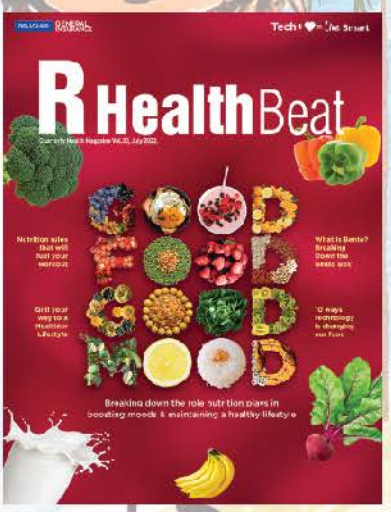

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