Childhood disorders and where to get help

a ADHD

Children experience difficulties in certain behaviour, including inattention, hyperactivity and impulsivity.
Contact (CT): Eversdal Primary School ADHD support group 021 976 8134 or info@eversdal.co.za
Durbanville ADHD Support Group tbeugger@sars.gov.za
Contact (National): ADHASA Stuart Wilson: 011 888 7655, info@ADHASA.co.za or visit adhdsupport.co.za

Angelman syndrome

This genetic disorder causes a variety of neurological problems, including delays in development, speech problems, jerky or trembling movements, seizures and trouble with balance.
Contact: Shawn or Alida: 039 737 4613 or phiz@mweb.co.za; Angelkids (Angelman Syndrome Families in South Africa) Ronel: 082 727 9558, angels1@vodamail.co.za or visit angelkids.webs.com; Angelman Syndrome in South Africa Facebook group; The Angelman Syndrome Forum visit angelmanforum.org

Apert syndrome

Children born with this congenital disorder usually have a malformed skull and face, hands and feet.
Contact: Cranio Kids (All Craniosynostosis disorders) Robyn Rondi: 082 601 8585, robyn.rondi@hotmail.com or visit craniokids.co.za; Online community forum apert.org; Apert Support Group and Children's Craniofacial Groups on Facebook

Apraxia

This disorder affects the ability of children to communicate and control fine and gross motor movements.
Contact: Apraxia-kids Association visit apraxia-kids.org

Asperger's syndrome

This condition falls into the autism spectrum and affects children's ability to socialise and communicate.
Contact (CT): ASCON Support Group (Asperger Connections) Avril: 021 715 5255 or ameaker@telkomsa.net
Contact (DBN): Action in Autism 031 207 4858 or info@autismsouthafrica.org
Contact (JHB): Asperger's Support Lauren Schrempel: 012 993 4628, 083 309 8654 or laurenschrempel@yahoo.com

Auditory Processing Disorder

Children have difficulty processing the sounds they hear, rather than with their hearing.
Contact (CT): I Can Development Centre (for telephonic advice on block therapy and inclusive education) Ali Smeeton: 084 605 0821 or visit ican-sa.co.za
Contact (JHB): I Can Development Centre Ilse Carr: 082 338 4680 or visit ican-sa.co.za

Autism

A developmental disorder that affects the brain's development of social and communication skills.
Contact (CT): Autism South Africa 011 484 9909, info@autismsouthafrica.org or visit autismsouthafrica.org
Autism Western Cape 021 557 3573, support@autismwesterncape.org.za or visit autismwesterncape.org.za
Contact (DBN): Action in Autism 031 207 4858 or info@autismsouthafrica.org
Contact (JHB): Autism South Africa 011 484 9909, info@autismsouthafrica.org or visit autismsouthafrica.org
Association for Autism 012 993 4628 or afautism@iafrica.com
Ernie Els Autism Foundation Kerri: 011 484 7254 or kerri-lyn.kelly@ernieels.com

b Bipolar disorder

Children experience moods, feelings, thoughts and behaviour that range from extreme highs to extreme lows.
Contact (CT): Western Cape Bipolar Support Association southern suburbs Jay: 072 424 1812 or Michelle 082 412 4448; Western Cape Bipolar Support Association northern suburbs Jay: 072 424 1812 or Michelle 082 412 4448, info@bipolar.co.za or visit bipolar.co.za ; Online support group bipolarsa.org
Contact (DBN): Bipolar Support Group Sister Pillay: soobashni.pillay@lifehealthcare.co.za or visit saida.org.za
Contact (JHB): Johannesburg Bipolar Support Association Linda Trump: 011 485 2406

c Central Auditory Processing Disorder

See Auditory Processing Disorder

Cerebral Palsy

This is an umbrella term that refers to conditions where the brain has been injured, affecting the child's movement, motor control, muscle control, perception and communication.
Contact (CT): Western Cape Cerebral Palsy Association 021 685 4150, secretary@wccpa.org.za or visit cerebralpalsybaby.blogspot.com, galliringo.blogspot.com or cpblogs.org.au/heydad
Contact (DBN): Crest and Quac (Daycare for CP children) Paula (KZN Cerebral Palsy Association): 031 700 3732 or 031 700 3956, paula.kzncpa@iafrica.com or visit kzncerebralpalsy.co.za
Contact (JHB): Cerebral Palsy Association 011 683 3390 or visit cerebralpalsybaby.blogspot.com, galliringo.blogspot.com or cpblogs.org.au/heydad

Cleft lip and palate

This occurs when the lip and/or palate don't join together before birth, leaving a gap.
Contact: Cleft Friends Helena: 082 393 1206, 079 527 1504, helena@cleftfriends.co.za or visit cleftfriends.co.za
Cleft Pals 011 788 9759

Congenital heart defects

These are structural defects present in the heart at birth. Children may exhibit poor development or growth, a heart murmur, shortness of breath or respiratory infections.
Contact (CT): Child Care Information Centre (based at Red Cross Children's Hospital) Val Hoy: 021 689 1519
Contact (DBN): Heart and Stroke Foundation 031 261 9050, kzn@heartfoundation.co.za or visit heartfoundation.co.za
Contact (JHB): Walter Sisulu Paediatric Cardiac Foundation Lynda Bleazard: 011 257 2017 or visit wspcca.org.za

Cornelia de Lange disorder

A genetic disorder that affects physical and intellectual development. Children may experience heart problems, speech delay, mental problems and behaviour problems.
Contact: CdLS-Kids Yahoo group online support or visit cdlusa.org

Cystic Fibrosis

Children with this condition develop a build-up of thick, sticky mucous in their lungs, digestive tract and other parts of the body, causing breathing problems, lung infections, poor growth, infertility and other problems.
Contact (CT): Cystic Fibrosis Association Support Group: Ruth Ireland 021 557 0323, Cheryl Vermeulen 021 790 8833 or visit sacfa.org.za
Contact (DBN): KZN Cystic Fibrosis Association Ashleigh: 071 602 2966, info@cysticfibrosis.co.za or visit cysticfibrosis.co.za
Contact (JHB): The Cystic Fibrosis Association support group – Alan Dunn 011 294 3849

Dandy-Walker syndrome

This congenital disorder causes a brain malformation. Symptoms may include slow development of motor skills, enlargement of the skull, particularly at the back, as well as increased intracranial pressure.
Contact: Dandy Walker Syndrome Support Group on Facebook or visit dandy-walker.org

Deafness/hearing loss

Hearing loss occurs when a part or parts of the ear do not function properly.
Contact (CT): Deaf Federation of SA 021 683 4665 or visit deafsa.co.za; Deaf Community of Cape Town Amanda: 021 671 6385
Contact (DBN): The KZN Blind and Deaf Society Belinda Naidoo: 031 309 4991, 082 868 000 or rehab@nbds.org.za
Contact (JHB): Deaf Federation of South Africa 011 482 1610; Hi Hopes Claudine Storbeck or Selvarani Moodley: 011 717 3750, claudine.storbeck@gmail.com or selvarani.moodley@wits.ac.za

Developmental delays

This is when a child is consistently late in reaching developmental milestones, including language, fine and gross motor skills, cognitive ability and social skills.
Contact (CT): I Can Development Centre Ali Smeeton (for telephonic advice): 084 605 0821 or visit ican-sa.co.za
Contact (DBN): I Can Development Centre Ali: 084 605 0821 or visit ican-sa.co.za
Contact (JHB): I Can Development Centre Ilse Carr: 082 338 4680 or visit ican-sa.co.za; SpiritedKidz Adi de Hoop: info@spiritedkidz.za.org or visit spiritedkidz.za.org

Down's syndrome

This condition occurs when children are born with an extra chromosome, causing differences in how their bodies develop and giving them a distinctive appearance.
Contact (CT): Down syndrome Support Cape (based at Red Cross Children's Hospital) Fazia Saban or Val Hoy: 021 658 5610 or fsaban@webmail.co.za
Contact (DBN): Down Syndrome Association KZN Caroline Willis: 031 464 2055, downskzn@iafrica.com or visit downsyndrome.org.za
Contact (JHB): Down Syndrome SA 0861 369 672, 011 484 8890 or visit downsyndrome.org.za; Down Syndrome Association 011 484 6116

Dwarfism

Dwarfism refers to people who are short in stature as a result of any number of medical conditions.
Contact: Little People of South Africa 072 077 2318; Raising Leah (online support group), Charmaine: 072 374 6233 or visit raisingleah.wordpress.com

Dysfunction of Sensory Integration (Sensory Integration Dysfunction)

This is the inability of the brain to organise sensory information as it comes through from the senses. It can impact on a child's ability to function and learn.
Contact: South African Institute of Sensory Integration Aletta Kietzmann: 012 362 5457 (Tuesday and Thursday), saisi@uitweb.co.za or visit instsi.co.za

Ehlers-Danlos syndrome

Children who suffer from this condition have a defect in the collagen of their connective tissue, resulting in joints that are loose or unstable, skin that is fragile and can bruise or tear easily, muscle or joint pain, poor muscle tone and other problems.
Contact: Ehlers-Danlos Parental Support Group Facebook page or visit ednf.org

Epilepsy

A neurological disorder that causes a person to have seizures or fits as a result of unusual electrical energy in the brain.
Contact (CT): Epilepsy South Africa (the Western Cape branch: Lansdowne) 021 703 9420, wcape@epilepsy.org.za
Contact (DBN): Melanie Nobin: 031 309 1370, 031 309 1661 or visit epilepsy.org.za
Contact (JHB): Magdalena Kruger: 011 816 2040 or visit epilepsy.org.za
Contact (national): Epilepsy SA 0860 374 537

Foetal Alcohol syndrome

This condition occurs when mental and physical defects develop as a result of alcohol crossing the placenta.
Contact (CT): Sanca 021 945 4080/1, sanca@sancawc.co.za or visit sancawc.co.za
Contact (DBN): Sanca 031 202 2241 or visit sancadbn.co.za
Contact (JHB): Sanca (national office) 011 781 6410, 011 726 4210 or visit sanca-jhb.org.za

Fragile X syndrome

This genetic disorder is a result of changes in the X chromosome and causes mental retardation. As boys only have one X chromosome, it tends to affect them more severely.
Contact: Fragile X (only if your doctor can't recommend anyone) Luisa Potenza: 011 624 0655, 076 514 3553 or visit lula@icon.co.za

Guillain-Barre syndrome

A rare disorder that affects the peripheral nervous system, which controls muscle movement and communicates sensory information to the brain. Complications may arise when the breathing muscles are affected. However, this disorder and its symptoms are usually temporary.
Contact: Guillain-Barre Syndrome Support Phyllis Fourie: 084 944 4488, phyllis@aurorahospital.co.za or visit guillainbarresindroom.co.za

Hypotonia

This describes a state of low muscle tone (different to muscle weakness) and can be caused by a variety of other disorders. Symptoms include floppiness in babies, delays in reaching developmental milestones, and difficulty in feeding or breathing.
Contact: Hypotonia Facebook page

Jacobsen syndrome

A rare congenital disorder caused by loss of genetic material. Children with this condition usually display distinctive facial features, such as wide set eyes and low set small ears.
Contact: Jacobsen syndrome Awareness visit jacobsenssyndromeawareness.com

Juvenile diabetes (Diabetes mellitus type 1)

Children with this form of diabetes can't produce insulin, which is responsible for getting glucose into the cells to create energy. Symptoms can include thirst,

hunger, frequent urination, weight loss and feeling tired.
Contact: Sugarbabes Foundation Eldice Ngcobo (the foundation organises camps): 031 266 1280, 072 695 3416 or sgrbbfoundation@gmail.com; The Dia Bear Club diabear1@absamail.co.za or visit diabear.co.za; SweetkidsSA Yahoo group online support; Diabetes South Africa 011 886 3765, national@diabetessa.co.za or visit diabetessa.co.za

Juvenile rheumatoid arthritis

This autoimmune condition is characterised by joint pain and swelling in children under 16 years. Children may show signs of stiffness or limping, have sore joints, experience a fever or rash and may have eye inflammation.
Contact: Arthritis Kids SA Di Crossman: 011 518 7129, 071 888 1682 or dcrossma@its.jnj.com
Arthritis Kids SA Facebook page

k Kawasaki disease

This is an autoimmune disease that causes inflammation in blood vessels, affecting the body's organs as well as the hands, feet, mouth, eyes and throat.
Contact: Kawasaki Disease Foundation of South Africa Mark: 031 539 3023, 084 231 3418, marksatiya@yahoo.com

Klinefelter syndrome

In this disorder, boys are born with an additional X chromosome, so while most males are XY, males with this condition are XXY. Some symptoms include reduced fertility or infertility, irregular testicular function, developed breast tissue and some boys may also develop psychosocial problems.
Contact: 47xxy Klinefelters syndrome support Facebook page

Krabbe disease

A rare degenerative disorder where the myelin sheath that surrounds the nervous system starts to break down and brain cells are destroyed. This is an inherited disease, and symptoms can include rigidity, fever, and irritability, slowing of the development of motor skills, hearing loss, difficulty eating and blindness.
Contact: Krabbe Kids visit krabbes.com

l Landau-Kleffner syndrome (Acquired epileptic aphasia)

Children with this neurological disorder suddenly or gradually lose the ability to understand or express language (aphasia). These symptoms are often accompanied by seizures.
Contact: Landau-Kleffner Information and Support Group Facebook page

Laryngomalacia

This is a common congenital defect where the soft, underdeveloped cartilage of the larynx collapses when the baby inhales. This causes a narrowing of the air passage, which results in a squeaky sound when the baby breathes.
Contact: Laryngomalacia Support Group Facebook page

m Mental retardation

This occurs in children under 18 years of age, when they have a below average intelligence quotient. Children may present with delays in language and motor development, difficulty in learning social norms, and difficulty in developing memory and problem solving skills.
Contact (CT): Cape Mental Health 021 447 9040 or visit capementalhealth.co.za
Contact (DBN): Durban and Coastal Mental Health (daycare centres) Thembi or Priya: 031 207 2717, thembi@dcmh.co.za or visit dcmh.co.za
Contact (JHB): South African Federation for Mental Health 011 242 9600; Gauteng Mental Health 011 614 6853

Metachromatic leukodystrophy

An inherited disorder caused by a deficiency of the enzyme arylsulfatase A, which results in a toxic build-up of sulfatides and damages the nervous system, liver, kidneys and other organs. Symptoms include loss of muscle tone and control, rigidity, delays in development, loss of vision, decreased mental ability, seizures and paralysis.
Contact: Families and their children with Leukodystrophy Facebook page

Missing limbs

This occurs when a child is born without a limb, or loses a limb due to trauma or for medical reasons.
Contact (CT): Western Cape Association for Persons with Disabilities visit apd-wc.org.za
Contact (DBN): Association for Persons with Physical Disabilities KZN Cheryl Naidoo or Azad Ismail: 031 403 7041 or apdkzn@mweb.co.za
Contact (JHB): Association for the Physically Disabled 011 646 8331 or visit apdjhb.co.za

Muscular dystrophy

This group of hereditary disorders affects the muscles of the body, causing them to lose tissue and get weaker over time. There are many different forms, so symptoms will differ.
Contact (CT): Muscular Dystrophy Foundation of SA Maxine Strydom (Parent Project SA): 083 290 6695, maxine@riverhillprop.com, cape@mdsa.org.za or visit mdsa.org.za
Contact (DBN): The Muscular Dystrophy Foundation of South Africa Maxine Strydom: 083 290 6695, maxine@riverhillprop.com or visit mdsa.org.za
Contact (JHB): The Muscular Dystrophy Foundation of South Africa 011 472 9703, 011 472 9824, gauteng@mdsa.org.za or visit mdsa.org.za

n Neurofibromatosis

In this genetic condition, non-cancerous tumours grow from the nerve tissue, affecting the spinal cord, brain, skin and other parts of the body. A defining sign is café-au-lait coloured spots on the body, while other symptoms can include seizures, blindness, freckling in the underarm or groin area, tumours on or under the skin and pain from affected nerves.
Contact: South African Neurofibromatosis Association 011 716 4071; Neurofibromatosis Support Facebook page

o Obesity

Someone is considered obese when their body fat has become excessive and will impact on their health, often reducing their lifespan.
Contact (CT): Overeaters Anonymous Muizenberg – Benita: 021 788 3070 or 084 645 2474; Kenilworth – Sarah: 083 556 5057; City Bowl – Sharon: 021 790 0268 or 082 973 3099; Fish Hoek – Ainsley: 083 518 6680
Contact (DBN): Overeaters Anonymous Chris: 083 409 8309, andrewss@iafrica.com or visit oa.org
Contact (JHB): Overeaters Anonymous 011 640 2901 or visit oa.org

p Paediatric Primary Immune Deficiency

A congenital disorder where children are born with cell defects which prevent the immune system from functioning properly, impacting on the body's ability to prevent infection.
Contact: Pinsa (Primary Immunodeficiency Network of South Africa) Mariana du Toit (secretary): 082 365 4663, pinsahelp@mweb.co.za or visit pinsa.org.za

Pierre Robin syndrome

This congenital condition causes babies to be born with malformed facial features, including a smaller lower jaw, a tongue that falls back into the throat and often a cleft soft palate. They are likely to experience breathing and feeding difficulties, and ear infections.

Contact: Pierre Robin Foundation Leigh Parkes: 082 410 3197, info@pierrerobin.org.za or visit pierrerobin.org.za
Pierre Robin Sequence Foundation Facebook page

Prader-Willi syndrome

A genetic congenital condition that causes decreased muscle tone, a continuous feeling of hunger and underdeveloped genitals.

Contact: Prader-Willi Syndrome Association of South Africa Rika Du Plooy: 012 344 0241, Janet Legemaate: 031 767 4493, chairperson@praderwilli.org.za or visit praderwilli.org.za

Primary Immune Deficiency Disorder

See Paediatric Primary Immune Deficiency

Rett syndrome

This is a neurodevelopmental disorder that affects girls more frequently than boys. It presents with a decrease in the rate of development and growth, as well as the loss of purposeful hand movements, verbal skills, balance and coordination.

Contact: My Daughter Has Rett Syndrome: A Family Forum for Rett Syndrome Support Facebook page or visit rettsyndromesouthafrica.com

Reye's syndrome

A rare disease affecting the organs of the body, most specifically the liver and brain, and most commonly occurring after a viral infection.

Contact: Reye's Syndrome Awareness Facebook page

Rubinstein-Taybi syndrome

This genetic disorder is characterised by distinctive facial features, broad thumbs and toes, short stature and degrees of learning disabilities.

Contact: RTS South Africa Jacqui Tooke: 084 666 9566, rts.southafrica@gmail.com or visit rts-southafrica.weebly.com or matthewtooke.blogspot.com; Rubinstein-Taybi visit rubinstein-taybi.org

Sjogren's syndrome

This autoimmune disorder causes the body to attack the cells that produce tears and saliva, with the main symptoms being dry mouth and dry eyes, although other parts of the body that need moisture may also be affected, including the skin, nose, joints, lungs and brain.

Contact: Sjogren's World online support group visit sjsworld.org

Spina Bifida

A congenital condition in which the spinal cord and backbone do not fuse, leaving an opening in the spine. Some other problems that could be experienced include poor bladder control, weakness in the feet and legs, or paralysis in the legs.

Contact (CT): Child Care Information Centre Val Hoy: 021 689 1519 at Red Cross Children's Hospital

Contact (national): Spina Bifida and Hydrocephalus Louise Muller: 011 475 1460

Tourette syndrome

TS is a neurological condition where people experience repetitive, involuntary movements and vocal sounds called tics. In severe cases the tics may result in the person hurting himself, uttering swear words or repeating the phrases of others.

Contact: Dystonia Association of South Africa (Movement disorders) Karin Willemse: 011 326 2112 or karin.pasa@tiscali.co.za; Tourette Syndrome support group 011 326 2112 or 082 357 6586; Mental Health Information Centre 021 938 9229, mhic@sun.ac.za, or visit mentalhealthsa.org.za; Tourette Syndrome Association online support visit tsa-usa.org

Turner syndrome

This condition affects girls, and occurs when a female is missing part or all of the second X chromosome in some or all of her cells. Symptoms include small stature, puffy hands or feet, webbing at the neck and heart defects. Girls may also have problems with fertility and hearing.

Contact: The Turner Syndrome Group of South Africa Jo-Anne Richards: 082 453 2591, josierichards@gmail.com or visit saida.org.za

Visual impairments – blindness

Low vision, legally blind and blindness are degrees of visual impairment, and may be congenital or the effect of various disorders or injury to the eyes.

Contact: Association for Visually Impaired Children support group 011 613 3589; Johannesburg Society for the Blind 011 613 8241; Retina SA Claudette Medefindt: 011 622 4904 or 083 306 5262. National helpline: 0860 59 59 59 or visit retinasa.org.za

Waardenburg syndrome

An inherited genetic disorder that may cause children to experience hearing loss and changes in the pigmentation of their hair and eyes.

Contact: Cranio Kids Robyn Rondi: 082 601 8585, robyn.rondi@hotmail.com or visit craniokids.co.za

Williams syndrome

This congenital disorder typically causes an elfin appearance in children, as well as heart defects and mental disability.

Contact: Williams Syndrome Support Group in South Africa Magda Coetzee: 084 574 2926 (South African number) or 00264 632 25927, 00264 8147 07362 (Namibian numbers) or Tanya Holtzhausen: 082 778 8429, williamsyndromesa@gmail.com

General support

Autoimmune Illness Support Forum
Facebook page
South African Inherited Disorders Association
011 489 9213 or visit saida.org.za
Special Needs Support Group
Facebook page
Whizz Kidz Special Needs Centre
Disabilities include autism spectrum disorders, learning disabilities, Apraxia, Rett syndrome, and Down's syndrome Deborah King: 031 701 1490, whizzkidzsnc@mweb.co.za or visit whizz-kidz.co.za