

MONICA BERRY

Monica Berry is a 14-year-old Caucasian girl who has lived in foster care for the past 12 months. Monica is under the jurisdiction of the State because her 31 year-old mother, Ms. Eleanor Berry, overdosed on methamphetamines and alcohol and was brought to the Emergency Room. Monica was home alone for the previous three days. Monica's mother acknowledges that she is addicted to both alcohol and prescription and non-prescription drugs. The court ruled that if left untreated, she would be unable to appropriately care for Monica and keep her safe. Monica's father died in an automobile accident when Monica was 2 years old. The DHS caseworker conducted a diligent relative search and no suitable kinship placement was available to care for a 14 year-old girl with the need for specialized educational, behavioral, and medical needs. The Indian Child Welfare Act (ICWA) is not applicable because it was determined by the court that ICWA does not apply.

Monica was in care once previously. Her 9 year-old twin brothers were taken into custody from the hospital at birth. They were born medically fragile met the criteria for Fetal Alcohol Syndrome. They were unable to regulate their body temperatures and were fed through a g-tube. They were placed in a non-relative foster care placement specialized to serve children with Intellectual and Developmental Disabilities (IDD). Ms. Berry relinquished the twins for adoption and expressed the belief that the boys would receive the care that they deserved. Subsequently, the foster parents adopted the boys when they were 18 months old.

Monica was also removed from the home when her brothers were removed from their mother's care. She was five years old at the time. Monica's mother made sufficient progress

during the next year such that the court determined that it was safe for Monica to be returned to her mother just after her 6th birthday.

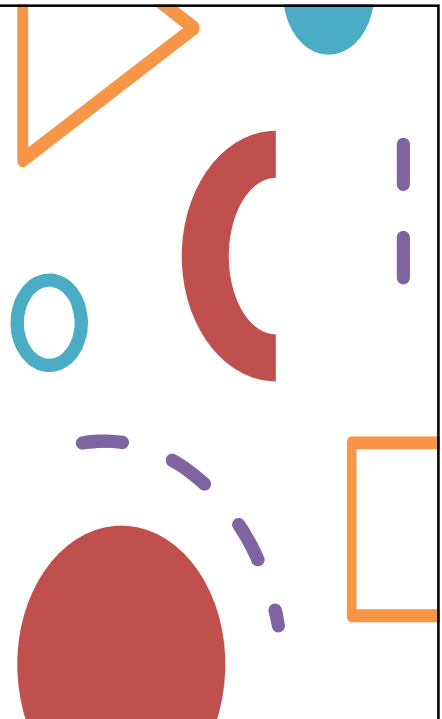
Monica resided with her mother for the next eight years. She attended several different schools during this time. She was eligible to receive Special Education services and she has an Individual Support Plan (ISP) that addresses cognitive/developmental delays and her need for help in the reading, arithmetic, and speech. Monica also receives services to address her behavioral issues. The behavioral specialist reports that she has trouble concentrating and staying focused, is impulsive and belligerent, displays poor judgment, and does not seem to respond to disciplinary strategies that are typically used in an educational setting.

When the Citizen Review Board (CRB) reviewed her file 6 months ago, they recommended that Monica be assessed for Fetal Alcohol Spectrum Disorder. Although she did not have any physical signs of the disorder, several factors were concerning: Monica's mother disclosed that she used alcohol and substances throughout her life; her brothers were identified as having FASD; and Monica's developmental and behavioral characteristics were consistent with FASD.

A Trauma-Informed Understanding of Children with Intellectual and Developmental Disabilities in a Child Welfare Context: A Facilitated Discussion for Oregon Citizen Review Board Members

Sarah Dababnah, Kathryn S. Collins, Emily Lee, Melissa H. Bellin, Molly H. Chinoy, Deborah P. Valentine

This project was supported by The Substance Abuse and Mental Health Services Administration, National Child Traumatic Stress Network.



Learning Objectives

Define	Explain	Describe	Discuss	Construct
Define intellectual & developmental disabilities (IDD) and the use of respectful language	Explain the ways CRB members can better understand the needs of children with IDD in a child welfare context. Explain trauma-informed approach	Describe the relationships between IDD, child maltreatment & foster care	Discuss the impact of trauma on children with IDD & their needs Discuss effective communication with parents with IDD	Construct service recommendations for children with IDD

Identity and Person-First Language

Person-first language emphasizes the person, not their disability; for example:

- Instead of “handicapped,” say “**person who uses a wheelchair**,” to **emphasize abilities and not limitations**.
- Instead of “normal,” say “**non-disabled person**” or “typical” in order to avoid characterizing people with disabilities as “abnormal.”
- Instead of “birth defect,” say “**born with ___**” in order to not imply a person is “defective” or broken.

Identity-first language, some individuals prefer identity-first language, for example:

- “An autistic person” (versus first-person language, “a person with autism”).
- When possible, ask an individual with a disability their preferences. An individual’s preference about how they want to be addressed is all that matters.

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Defining Disability Broadly






A disability is a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a child's ability to engage in certain tasks or actions or participate in typical daily activities and interactions.

- There are many definitions of disabilities.
- Disabilities vary in severity and need to be seen on a spectrum of impact to the child and family.

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Five Categories of Disabilities and Other Health Conditions

 Developmental	<ul style="list-style-type: none"> • These disabilities generally manifest during childhood and impacts personal, social, academic, or occupational functioning. • Examples include: Intellectual Disability, Autism, AD/HD
 Physical/Motor	<ul style="list-style-type: none"> • A physical condition that impacts a youth's motor function • Examples include: Spina Bifida, Cerebral Palsy, Multiple Sclerosis
 Visual or Hearing	<ul style="list-style-type: none"> • A visual difference that may impact educational performance or development; or hearing difference whether permanent or fluctuating that adversely impacts educational performance
 Emotional Disturbance	<ul style="list-style-type: none"> • A mental or behavioral condition that is not explained by an intellectual, sensory, or health condition that is long term and impedes a child's functioning in their social environment. • Examples include: Depression, Anxiety, Post Traumatic Stress
 Medical Condition	<ul style="list-style-type: none"> • Conditions other than those noted above which require special medical care such as chronic illnesses • Examples include: HIV/AIDS, Asthma, Cancer

A Focus on Intellectual and Developmental Disabilities (IDD)

- The National Institute of Child Health and Human Development ([2012](#)) defines IDD as “disorders that are usually present at birth and that negatively affect the trajectory of the individual’s physical, intellectual, and/or emotional development.”
- A developmental disability is an umbrella term that refers to a range of diagnoses, including intellectual disability.
- Individuals with a developmental disability do not necessarily have an intellectual disability. For example, only about [31% of children with autism](#) also have an intellectual disability (Baio et al., 2018).
- Approximately [1 in 6 US children](#) ages 3-17 years old (~17%) have a diagnosed developmental disability (Zablotsky et al., 2019).

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IDD Definitions Vary by Source

- Lack of consistency between how government agencies and service organizations define IDD
- [Common examples of IDD](#) include Down Syndrome, Autism, Spina Bifida, Fetal Alcohol Spectrum Disorders, and Cerebral Palsy (CDC, 2019).
- Children with disabilities commonly receive school-based services through the Individuals with Disabilities Education Act (IDEA), which has its own definition of disability.

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Individuals with Disabilities Education Act (IDEA)

- IDEA entitles children with disabilities a free and appropriate public education. It covers developmental delays (only for children up to age 9) and [13 categories of disabilities](#) (U.S. Department of Education, 2018) for children of all ages (up to age 21):
 1. Autism
 2. Deafness
 3. Deaf-blindness
 4. Emotional disturbance (e.g., anxiety and other mental health issues)
 5. Hearing impairment
 6. Intellectual disability
 7. Multiple disabilities (e.g., intellectual disability-blindness)
 8. Orthopedic impairment (e.g., cerebral palsy)
 9. Other health impairment (e.g., ADHD, asthma)
 10. Specific learning disability (e.g., dyslexia)
 11. Speech or language impairment (e.g., stuttering)
 12. Visual impairment
 13. Traumatic brain injury
- In order to receive services under IDEA, the child must fit into one of the above categories *AND* must need special education in order to make academic progress. A disability alone does not qualify a child for services under IDEA.
- Individual states provide guidance on how to define the above categories; thus, there are state-by-state variations on who qualifies. Visit Oregon's [IDEA website](#) to learn more.

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Impact of IDD on Development

- An IDD may impact an individual's development and/or certain body systems.
- At times, there may be an overlap.

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Causes of IDD

- For many IDD, the cause is **idiopathic** or **unknown**
 - Example: autism is suspected to result from a mixture of environmental and genetic causes, but scientists have not yet identified the precise cause.
- In some cases, the cause is known, and can result from a mix of one or more of the following factors:
 - **Genetic** (e.g., Fragile X, Prader-Willi, Williams, or Down syndromes)
 - **Environmental** (e.g., maternal or child lead exposure)
 - **Toxic exposures** (e.g., Fetal Alcohol Spectrum Disorders, which result from alcohol use during pregnancy)
 - **Preterm birth or low birthweight**
 - **Infections** (including maternal infections during pregnancy)
 - **Head trauma or other injuries**
 - **Metabolic issues** (e.g., high bilirubin levels in newborns can lead to kernicterus)
 - **Malnutrition**

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Children with IDD in the Child Welfare System

Children with disabilities are:

- Three to Four times more likely to experience acute and chronic child maltreatment ([Sullivan & Knutson, 2000](#))
- Two times as likely to be placed in foster care ([Lightfoot et al., 2011](#)) and permanently live in non-kin care ([Romney et al., 2006](#))
- have a disrupted adoption ([Slayter & Springer, 2011](#))

The systems serving children with disabilities and child welfare often do not align, due to:

- different definitions of “disability” ([Liao et al., 2017](#))
- lack of training of service providers on people with disabilities ([Lightfoot & LaLiberte, 2006](#))
- service differences (child welfare services are mandatory and meant to be short-term; whereas IDD services are voluntary and often longer-term).

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Understanding Trauma and IDD



Children with IDD are at risk for multiple traumas:


- Three times more likely to be in families with domestic violence
- Four times more likely to be victims of crimes
- Two times more likely to be bullied



Several challenges exist to support children with IDD who have experienced trauma, including:

- Diagnostic overshadowing
- Inappropriate screening and assessment tools
- Lack of service provider training
- Assumptions made about children’s ability to engage in treatment
- Fragmented services


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Children of Color with Disabilities are Particularly Vulnerable

- Significant racial and ethnic health and diagnostic disparities for children with autism ([Mandell et al., 2009](#)) and other developmental disabilities ([Magaña et al., 2012](#)).
- Children of color, including Black and Native Americans, are overrepresented in the child welfare system (see [Child Welfare Information Gateway, 2016](#) for more information and readings)
- A comprehensive approach is needed to address both individual and community risk factors (e.g., poverty) along with racial factors (e.g., worker biases) that lead to disparities in child welfare system involvement (see [Putnam-Hornstein et al., 2013](#) for more information).
- The field needs to do more to understand the experiences of children of color with disabilities in the child welfare system.


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The Importance of Identifying Foster Children with IDD

Understanding need for specialized supports

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INFORMING FINDINGS


#3A

Has DHS ensured that appropriate services are in place to safeguard the child's safety, health, and well-being?

- Placement
- Safety
- Family contact
- Assessments
- Education
- Health
- Youth transition plan
- Cultural considerations



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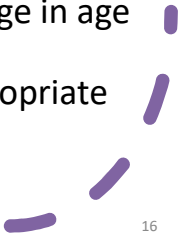


INFORMING FINDINGS

#3B

Has DHS taken appropriate steps to ensure that:

- 1) the substitute care provider is following the reasonable and prudent parent standard; and
- 2) the child has regular, ongoing opportunities to engage in age appropriate or developmentally appropriate activities?



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**INFORMING
FINDINGS**

#4

Has DHS made reasonable efforts to provide services to parents that make it possible for the child to safely return home?

- What services are provided?
- Are additional services needed?

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**INFORMING
FINDINGS**

#6

Have the parents made sufficient progress to make it possible for the child to safely return home?

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How to ask questions about IDD from the file and during the review meeting?

Brainstorm:

1. Has there been an assessment and diagnosis completed by an appropriate professional?
2. Is the child receiving the proper accommodations in the school?
3. Is there evidence that the parents understand the disability?
4. OTHERS?



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Case study: Monica



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Think about ...

How might DHS ensure that appropriate services are in place to safeguard Monica's safety, health, and well being?

- Assessments
- Accommodations
- ADA compliance
- School and education
- Community involvement



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Examples of CRB recommendations

- An educational assessment be conducted as soon as possible
- A psychological assessment be conducted before the next CRB review
- The concurrent plan be evaluated recognizing a child's special needs
- Determine if the "diagnosis" is accurate
- Others?

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WRAP UP

- Feedback
- Next steps

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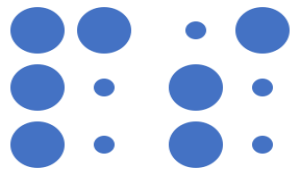
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A Guide for Youth with Disabilities and Special Healthcare Needs

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INTRODUCTION

This Guide for Youth with Disabilities and Special Healthcare Needs provides information on a range of chronic pediatric health conditions and developmental disabilities. To enhance the user's experience with the guide, we synthesized content across the following categories: developmental issues; physical/motor conditions; visual or hearing disabilities; emotional/behavioral disturbances, and medical conditions. Each topic area is paired with resource descriptions, inclusive of government (G) agencies and advocacy (A) resources, and website links (URLs). The government resources offer information from federal agencies such as the Centers for Disease Control (CDC), National Institutes of Health (NIH), and Substance Abuse and Mental Health Administration (SAMHSA). The advocacy resources include websites for non-governmental advocacy organizations and institutions focused on social justice, community integration, and overall quality of life for youth and their families.

While reviewing this guide, it is important to remember that many of the disabilities listed are comorbid, meaning an individual can experience them simultaneously. For example, children with cerebral palsy may also have intellectual disability. Also, our list is not exhaustive. You may encounter youth with rare conditions and will need to find additional resources. Finally, it is also important to be mindful of typical child and adolescent development. Two suggested resources include the CDC milestone page: <https://www.cdc.gov/ncbddd/actearly/milestones/index.html> and Pathway's website: <https://pathways.org/about/> Each of these websites offer resources for youth and their parents from a lifespan perspective (i.e., developmental stages).

Five Categories of Disabilities



Developmental

- These disabilities generally manifest during childhood and have impairments of personal, social, academic, or occupational functioning.
- Examples include: Intellectual Disability, Autism Spectrum, AD/HD



Physical

- A physical condition that impacts a youth's motor function
- Examples include: Spina Bifida, Cerebral Palsy, Multiple Sclerosis



Visual or Hearing

- A visual impairment that may impact educational performance or development; or hearing impairment whether permanent or fluctuating that adversely impacts educational performance



Emotional Disturbance

- A mental or behavioral condition that is not explained by an intellectual, sensory, or health condition that is long term and impedes a child's functioning in their social environment.
- Examples include: Depression, Anxiety, Post Traumatic Stress



Medical Condition

- Conditions other than those noted above which require special medical care such as chronic illnesses
- Examples include: HIV/AIDS, Asthma, Cancer

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Apraxia of Speech	Ataxia	Blindness	Anxiety Disorders	Acquired Immunodeficiency Syndrome (AIDS)/Human Immunodeficiency Virus (HIV)
Attention Deficit Hyperactivity Disorder	Brittle Bones/ Osteogenesis Imperfecta (OI)	Cataracts	Behavioral Disorders	Asthma
Autism Spectrum Disorder	Cleft Palate	Congenital Anomaly of the Eye	Feeding and Eating Disorders	Cancers
Cerebral Palsy	Congenital Talipes Equinovarus (Clubfoot)	Diabetic Retinopathy	Mood Disorders	Chronic Granulomatous Disease
Developmental Disabilities	Duchenne Muscular Dystrophy	Deafness and Other Communication Disorders	Posttraumatic Stress Disorder	Congenital Cystic Lung
Down syndrome	Dystonia	Glaucoma	Schizophrenia and Other Psychotic Disorders	Congenital Heart Defects
Dyslexia	Genetic and Rare Diseases	Retinal Detachment and Defects	Substance Abuse	Crigler-Najjar Syndrome
Fetal Alcohol Spectrum Disorders	Kernicterus			Crohn's Disease
Fragile X Syndrome	Multiple Sclerosis (MS)			Cushing's Syndrome
Intellectual Disability	Myasthenia Gravis			Cystic Fibrosis
Klienefelter's Syndrome	Neurological Disorders and Stroke			Diabetes and Digestive and Kidney Diseases
Learning Disorders	Paralysis			Encephalopathy Epilepsy
Prader-Willi syndrome	Rheumatoid Arthritis (juvenile)			Hemophilia/Bleeding Disorders
Prenatal Drug Exposure	Shaken Infant Syndrome			Hydrocephalus
Rett Syndrome	Seizure Disorder			Hypertension
Spina Bifida	Tic Disorders			Lead Poisoning
Stuttering	Tourette Syndrome			Leukemia
	Traumatic Brain Injury			Liver Disease
				Lupus
				Metabolic Disorders
				Microcephaly
				Nutritional Deficiency
				Pancreatic Disease
				Pollution-Related Illnesses
				Sarcomas
				Sickle Cell Anemia

Disability	Resource	Web URL	Description
DEVELOPMENTAL			
Apraxia of Speech	NIH – Apraxia of Speech (G)	https://www.nidcd.nih.gov/health/apraxia-speech	This page provides information on Apraxia of Speech including definitions, types, causes, symptoms, diagnosis, treatment, and additional resources for families.
	American Speech-Language-Hearing Association (A)	www.asha.org	The American Speech-Language-Hearing Association is the association for more than 200,000 members and affiliates who are speech-language pathologists, audiologists, and speech, language, and hearing scientists in the United States and internationally. They work to empower and support speech-language pathologists, audiologists, and scientists by advocating for those with communication and related disorders, advancing communication science, and promoting effective human communication.
Attention Deficit Hyperactivity Disorder	CDC – Attention Deficit Hyperactivity Disorder (ADHD) (G)	https://www.cdc.gov/ncbddd/adhd/index.html	This page provides information on ADHD including facts, symptoms, diagnosis, treatment, current research, data and statistics, articles, recommendations, and additional resources.
	Children and Adults with Attention-Deficit/Hyperactivity Disorder (A)	https://chadd.org	CHADD was founded in 1987 to aid and support parents and their children with ADHD. It is now the leading non-profit national organization for children and adults with ADHD. The organization’s volunteers provide support and education to parents, educators, and professionals.

Autism Spectrum Disorder	NIMH – Autism Spectrum Disorder (G)	https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml	This page provides information on Autism Spectrum Disorder including definitions, symptoms, diagnosis, and additional resources for families.
	Autism NOW (A)	https://autismnow.org	Autism Now is an initiative of The Arc and The Administration on Developmental Disabilities. This national autism resource and information center provides support and education for those impacted by Autism Spectrum Disorders and related conditions.
Cerebral Palsy	CDC – Cerebral Palsy (G)	https://www.cdc.gov/ncbddd/cp/facts.html	This page on the CDC website offers information on Cerebral Palsy including types, early signs, screening and diagnosis, treatment and intervention services, causes and risk factors, and resources for parents.
	Cerebral Palsy Foundation (A)	https://www.yourcpf.org/	The Cerebral Palsy Foundation was founded in the 1950s and provides funding for cerebral palsy research focused on finding new treatments that improve the quality of life and mobility for those impacted by cerebral palsy.
Developmental Disabilities	MedlinePlus – Developmental Disabilities (G)	https://medlineplus.gov/developmentaldisabilities.html	This page provides information on developmental disabilities including diagnoses and tests, symptoms, treatments and therapies, genetics, current research, and additional resources for children and families.
	The Arc (A)	https://thearc.org/	The Arc is an organization that works to advocate for those with developmental and intellectual disabilities. They achieve their goals through grassroots advocacy, program initiatives, community networks, and educational resources.

Down Syndrome	NIH – Down Syndrome (G)	https://ghr.nlm.nih.gov/condition/down-syndrome	This page offers information on Down syndrome including descriptions, frequency and causes, inheritance patterns, diagnosis and management resources, and additional material for families.
	National Down Syndrome Society (A)	https://www.ndss.org	The National Down Syndrome Society (NDSS) has worked to advocate for those with Down syndrome. The NDSS National Policy Center works with Congress and federal agencies to protect the rights of people with Down syndrome, and educates individuals to advocate on local, state and national levels.
Dyslexia	NIH – Dyslexia (G)	https://www.ninds.nih.gov/Disorders/All-Disorders/Dyslexia-Information-Page	This page provides information on dyslexia including definitions, treatment, prognosis, clinical trials, publications, and patient organizations.
	International Dyslexia Association (A)	https://dyslexiaida.org/dyslexiacon20/	The International Dyslexia Association is dedicated to helping individuals with dyslexia and their families through research, treatment, resources, services, and education.
Fetal Alcohol Spectrum Disorders	CDC – Fetal Alcohol Spectrum Disorders (G)	https://www.cdc.gov/ncbddd/fasd/facts.html	This page provides information on FASDs including causes and prevention, signs and symptoms, types, diagnoses, treatment, and resources for additional support.
	National Organization of Fetal Alcohol Syndrome (A)	https://www.nofas.org	The National Organization of Fetal Alcohol Syndrome (NOFAS) is dedicated to preventing prenatal exposure to alcohol, drugs, and other substances through advocacy work, support before and during pregnancy, education for the public and healthcare workers, and professional trainings.

Fragile X Syndrome	NIH – Fragile X Syndrome (G)	https://ghr.nlm.nih.gov/condition/fragile-x-syndrome	This page provides information on Fragile X syndrome including descriptions of the syndrome, frequency and causes, inheritance patterns, diagnosis and management, and additional resources.
	National Fragile X Foundation (A)	https://fragilex.org/	The National Fragile X Foundation supports those impacted by Fragile X Syndrome through advocacy and raising awareness, education, and research.
Intellectual Disability	CDC – Intellectual Disability (G)	https://www.cdc.gov/ncbddd/developmentaldisabilities/facts-about-intellectual-disability.html	This page provides information on intellectual disabilities including symptoms of intellectual disability and resources for families. The page also provides links to research and articles as well as educational materials for parents.
	American Association on Intellectual and Developmental Disabilities (A)	https://www.aaid.org/	The AAIDD provides information on intellectual disability and resources for families who are impacted. Their website offers educational materials, publications, news, policies, and additional resources. The association aims to promote progressive policies, quality research, effective practices, and human rights for those living with intellectual and developmental disabilities.
Klinefelter's Syndrome	NIH – Klinefelter syndrome (G)	https://ghr.nlm.nih.gov/condition/klinefelter-syndrome	This page provides information on Klinefelter syndrome including descriptions, causes, inheritance patterns, diagnoses, management, and additional resources.
	Association for X and Y Chromosome Variations (A)	https://genetic.org/variations/about-47xxy/	AXYS works to support individuals with extra X and/or Y chromosomes (for example, Klinefelter's syndrome) through proper education, promotion of research, and improvement of treatment options and access.

Learning Disorders	CDC – Learning Disorders (G)	https://www.cdc.gov/ncbddd/childdevelopment/learning-disorder.html	This page provides information on learning disorders in children including symptoms, treatment, and resources for both parents and healthcare providers.
	Learning Disabilities Association of America (A)	https://ldaamerica.org/types-of-learning-disabilities/	The LDA was started in 1963 by a group of parents and professionals who worked to provide necessary services to children and families impacted by learning disabilities. The association strives to empower individuals with learning disabilities, provide resources to students, and improve overall awareness and education surrounding learning disabilities.
Prader-Willi Syndrome	NIH – Prader-Willi Syndrome (G)	https://ghr.nlm.nih.gov/condition/prader-willi-syndrome	This page provides information on Prader-Willi syndrome including descriptions, frequency and causes, inheritance patterns, diagnosis and management, and additional resources.
	Prader-Willi Syndrome Association (A)	https://www.pwsausa.org/	PWSA (USA) was organized in 1975 as a nonprofit corporation and supports those with Prader-Willi syndrome through family and medical services, research, advocacy and public policy. They aim to raise awareness of PWS and enhance quality of life for patients.
Prenatal Drug Exposure	NCBI – Developmental Consequences of Fetal Exposure to Drugs (G)	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4262892/	This article details developmental consequences of fetal drug exposure including impacts of specific drugs, clinical implications, and future directions of research.
	March of Dimes (A)	https://www.marchofdimes.org/index.aspx	March of Dimes is a foundation that works to support mothers and their babies during and after pregnancy, advocate for better health policies, fund research, and educate medical professionals on best practices.

Rett Syndrome	NIH – Rett syndrome (G)	https://ghr.nlm.nih.gov/condition/rett-syndrome	This page provides information on Rett syndrome including descriptions, causes, inheritance patterns, diagnosis and management, and additional resources.
	Rettsyndrome.org (A)	https://www.rettsyndrome.org/	The mission of this group is to advance research to cure Rett syndrome and support families through education and community connection. Advocates work to raise awareness about Rett syndrome and motivate others to further research and treatment efforts.
Spina Bifida	CDC – Spina Bifida (G)	https://www.cdc.gov/ncbddd/spinabifida/facts.html	This page provides information on Spina Bifida including types, diagnosis, treatments, causes, and resources.
	Spina Bifida Association (A)	https://www.spinabifidaassociation.org	The mission of the Spina Bifida Association is to build a better and more supportive world for all those impacted by Spina Bifida. The association offers in-person and online education programs featuring medical experts, parents, and adults with Spina Bifida.
Stuttering	NIH – Stuttering (G)	https://www.nidcd.nih.gov/health/stuttering	This page provides information on stuttering including definitions and descriptions, diagnosis, treatment, current research, and additional resources.
	National Stuttering Association (A)	https://westutter.org/	The National Stuttering Association (NSA) is a non-profit organization committed to bringing hope and empowerment to children and adults who stutter through support, education, advocacy work, and research. The NSA also provides treatment referrals and raises the consciousness of the general public about the disorder.

PHYSICAL/MOTOR			
Ataxia	NCBI – Ataxia (G)	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5567218/	This article provides information on ataxia including current research, symptoms, terms, neuroanatomy, classification and etiologies, evaluations, diagnostic testing, and additional resources.
	National Ataxia Foundation (A)	https://ataxia.org/	NAF is a nonprofit organization formed to support those impacted by Ataxia. The foundation advances Ataxia research and provides access to programs and resources for families.
Brittle Bones/ Osteogenesis Imperfecta (OI)	NIH – Osteogenesis Imperfecta (G)	https://ghr.nlm.nih.gov/condition/osteogenesis-imperfecta	This page provides information on OI including descriptions, causes, inheritance patterns, diagnosis and management, and additional resources.
	Osteogenesis Imperfecta Foundation (A)	https://oif.org/informationcenter/about-oi/	The OI foundation serves to support and improve the lives of those impacted by osteogenesis imperfecta through education, advocacy, and research. Staff members and volunteer workers provide support services to over 100,000 people each year.
Cleft Palate	CDC – Cleft Lip/Palate (G)	https://www.cdc.gov/ncbddd/birthdefects/cleftlip.html	This page provides information on cleft lip and cleft palate including causes and risk factors, diagnoses, treatment, and additional resources.
	Smile Train (A)	https://www.smiletrain.org/our-cause	Smile Train is an international children’s charity that provides training, funding, and resources to local medical professionals to perform cleft repair surgery, as well as space for patients to share their stories.

Congenital Talipes Equinovarus (clubfoot)	NCBI – Clubfoot (G)	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2759597/	This article provides information on the etiology and treatment of congenital talipes equinovarus (clubfoot).
	Clubfoot C.A.R.E.S. (A)	https://www.clubfootcares.org/	Clubfoot C.A.R.E.S. is a nonprofit advocacy organization formed by mothers of children with clubfoot. The organization strives to educate communities about clubfoot, increase awareness of nonsurgical treatments, and advocate for those impacted by clubfoot.
Duchenne Muscular Dystrophy	NIH – Duchenne Muscular Dystrophy (G)	https://www.genome.gov/Genetic-Disorders/Duchenne-Muscular-Dystrophy	This page provides information on Duchenne Muscular Dystrophy including descriptions, symptoms, diagnoses, treatment, inheritance patterns, and additional resources.
	Muscular Dystrophy Association (A)	https://www.mda.org/	The MDA works to support those impacted by muscular dystrophy, ALS, and related neuromuscular diseases. The association funds treatment research and provides quality care to families as well as sharing their stories. The MDA also provides guidance on fundraising, participating in events, and volunteering.
Dystonia	NIH – Dystonia (G)	https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Dystonias-Fact-Sheet	This page provides information about dystonia including symptoms, current research, classifications, treatments, and additional resources for those impacted.
	Dystonia Medical Research Foundation (A)	https://dystonia-foundation.org	Dystonia Medical Research Foundation (DMRF) is a non-profit organization focused on research and advocacy for those impacted by dystonia.

Genetic and Rare Diseases	Genetic and Rare Diseases Information Center (G)	http://rarediseases.info.nih.gov/GARD/	The Genetic and Rare Diseases Information Center (GARD) is a program funded by two parts of the National Institutes of Health (NIH): NCATS and the National Human Genome Research Institute (NHGRI). GARD provides the public with access to current, reliable, and easy-to-understand information about rare or genetic diseases.
	Rare Disease Legislative Advocates (A)	https://rareadvocates.org	RDLA is part of the EveryLife Foundation for Rare Diseases and functions to advocate for patients living with rare diseases as well as related organizations.
Kernicterus	CDC – Kernicterus (G)	https://www.cdc.gov/ncbddd/jaundice/facts.html	This page offers information on both jaundice & kernicterus including signs and symptoms, diagnoses, treatment, risk factors, and resources for parents.
	Parents of Infants and Children with Kernicterus (A)	https://pic-k.org/	Parents of Infants and Children with Kernicterus (PICK) is committed to education and prevention of kernicterus (KI) in addition to support and research for those impacted. Parents involved in PICK are passionate about educating communities about KI and the need for quality treatment.
Multiple Sclerosis (MS)	NIH – Multiple Sclerosis (G)	https://medlineplus.gov/multiplesclerosis.html	This page provides information on MS including diagnoses and tests, treatments and therapies, related issues, genetics, research, journal articles, and additional resources.
	National Multiple Sclerosis Society (A)	https://www.nationalmssociety.org/	The National Multiple Sclerosis Society works to eliminate MS and support patients living with MS. Members carry out the organization’s mission through advancing research, advocating for patients and their families, fundraising, and providing resources to MS communities.

Myasthenia Gravis	NIH – Myasthenia Gravis (G)	https://www.ninds.nih.gov/disorders/patient-caregiver-education/fact-sheets/Myasthenia-gravis-fact-sheet	This page provides information on myasthenia gravis including definitions, symptoms, causes, prevalence, diagnoses, treatments, prognosis, current research, and additional resources.
	Myasthenia Gravis Association (A)	http://www.mgakc.org/home-1.html	The MGA serves to aid those impacted by Myasthenia Gravis and foster supportive communities for patients and families. The MGA provides tools and resources and offers safe spaces for individuals and families and connects them with healthcare providers.
Neurological Disorders and Stroke	National Institute of Neurological Disorders and Stroke (G)	https://www.ninds.nih.gov	The National Institute of Neurological Disorders and Stroke is an Institute within the National Institutes of Health that aims to seek fundamental knowledge about the brain and nervous system and to use that knowledge to reduce the burden of neurological disease.
	American Stroke Association (A)	https://www.stroke.org/en/about-stroke	The American Stroke Association is a division of the American Heart Association. The association's website provides educational information on strokes as well as community and professional resources, resources for support and healthy living, and ways communities can get involved.
Paralysis (Paraplegic, Quadriplegic, Diplegic)	NIH – Paralysis (G)	https://medlineplus.gov/paralysis.html	This page provides information on paralysis and related conditions including symptoms, diagnoses, treatments, and additional resources.
	Christopher & Dana Reeve Foundation (A)	https://www.christopherreeve.org/	This foundation works to cure spinal cord injury through advancing research and supporting those

			impacted by paralysis through education, resources, funding, and advocacy efforts.
Rheumatoid Arthritis (juvenile)	CDC – Childhood Arthritis (G)	https://www.cdc.gov/arthritis/basics/childhood.htm	This page provides information on childhood arthritis including symptoms, diagnoses, treatments, and additional resources.
	Arthritis Foundation (A)	https://www.arthritis.org/diseases/juvenile-arthritis	The Arthritis Foundation promotes a network of support to those impacted by arthritis and juvenile arthritis. Members work to further research, advocate for meaningful change, and foster connections within arthritis communities.
Shaken Infant Syndrome	NIH – Shaken Baby Syndrome (G)	https://www.ninds.nih.gov/disorders/All-Disorders/shaken-baby-syndrome-information-page	This page provides information on shaken baby syndrome including definitions, treatments, prognosis, research publications, and additional resources.
	National Center on Shaken Baby Syndrome (A)	https://www.dontshake.org/	The National Center on Shaken Baby Syndrome is focused on promoting the health and wellness of infants through educating the public, pushing for research and policy change, and supporting caregivers, families, and health professionals.
Seizure Disorder	NIH – Epilepsies and Seizures (G)	https://www.ninds.nih.gov/disorders/patient-caregiver-education/hope-through-research/epilepsies-and-seizures-hope-through#3109_8	This page provides information on epilepsies and seizures including definitions, causes and types, risk factors, diagnoses, prevention, treatment, current research, and additional resources.

	American Brain Foundation (A)	https://www.americanbrainfoundation.org/diseases/seizure-disorders/	The American Brain Foundation furthers research on brain diseases and connects researchers and donors to find cures. They strive to improve treatments for those struggling with brain diseases and provide resources and education on brain diseases to increase awareness.
Tic Disorders	CDC – Diagnosing Tic Disorders (G)	https://www.cdc.gov/ncbddd/tourette/diagnosis.html	This page provides information on diagnosing tic disorders along with additional resources for those impacted by tic disorders.
	The Child Mind Institute (A)	https://childmind.org/topics/disorders/tourettes-and-tic-disorders/	The Child Mind Institute is a nonprofit that strives to improve the lives of children and families struggling with learning and mental health disorders, including tic disorders. This page on their website provides information on Tourette’s and tic disorders along with educational and treatment resources.
Tourette Syndrome	NIH – Tourette Syndrome (G)	https://www.ninds.nih.gov/Disorders/All-Disorders/Tourette-Syndrome-Information-Page	This page offers information about Tourette Syndrome including definitions, treatments, prognosis, clinical trials, patient organizations, and publications.
	Tourette Association of America (A)	https://tourette.org	The Tourette Association of America is a national non-profit organization dedicated to improving the quality of life for those impacted by Tourette and Tic Disorders.
Traumatic Brain Injury (TBI)	NCBI – Pediatric Traumatic Brain Injury (G)	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5341344/	This article details information on traumatic brain injuries in children including epidemiology, diagnosis and clinical features, types, secondary injury, management, treatments, outcomes, and additional resources.

	Brain Injury Association of America (A)	https://www.biausa.org/brain-injury/about-brain-injury/children-what-to-expect	The BIAA strives to help diagnose and treat those with brain injuries as well as increase public awareness and understanding of brain injuries. The association also works to advance brain injury treatment research and provide support and education to impacted families. This page explains what to expect in children who have experienced brain injuries.
VISUAL OR HEARING			
Blindness	NCBI – Blindness (G)	https://www.ncbi.nlm.nih.gov/books/NBK448182/	This article provides information on blindness including definitions, etiology, epidemiology, pathophysiology, treatment and management, and additional resources.
	American Foundation for the Blind (A)	http://www.afb.org	The AFB works to support those impacted by blindness through wide-scale research, education, community engagement, and advocate for policies and practices that serve to improve the lives of patients across the nation.
Cataracts	NIH – Cataracts (G)	https://www.nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/cataracts	This page details information on cataracts including types, symptoms, risks, causes, prevention, diagnoses, treatments, research, and additional resources.
	American Academy of Ophthalmology (A)	https://www.aao.org/about/who-we-are/overview	The American Academy of Ophthalmology works to advocate for patients and provide ophthalmic education to the public. The academy is a global community of eye physicians and surgeons who strive to set standards for ophthalmic education and provide quality eye care to patients.

Congenital Anomaly of the Eye	NIH – Eye Diseases (G)	https://rarediseases.info.nih.gov/diseases/diseases-by-category/9	This page provides a library of information on various eye diseases, such as congenital cystic eye and congenital disorders of glycosylation.
	Research to Prevent Blindness (A)	https://www.rpbusa.org/rpb/about/us/about-rpb/	RPB is a nonprofit organization that focuses on prevention, treatment, and elimination of diseases of the eye. RPB provides funding to support high-impact vision research and educate the public on eye conditions.
Diabetic Retinopathy	NIH – Diabetic Retinopathy (G)	https://www.nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/diabetic-retinopathy	This page provides information on diabetic retinopathy including types, symptoms, risk factors, causes, diagnoses, prevention, treatment, research, and additional resources.
	American Society of Retina Specialists (A)	https://www.asrs.org/patients/retinal-diseases/3/diabetic-retinopathy	ASRS is a retinal organization that serves as an advocate and source of comprehensive information and education on vitreoretinal diseases. The organization works to advance access to and quality of care for patients.
Deafness and Other Communication Disorders	National Institute on Deafness and other Communication Disorders (G)	https://www.nidcd.nih.gov	National Institute on Deafness and other Communication Disorders (NIDCD), part of the National Institutes of Health (NIH), conducts and supports research in the normal and disordered processes of hearing, balance, taste, smell, voice, speech, and language. The NIDCD’s mission is to improve the lives of the millions of people with hearing loss and other communication disorders, spanning functions of hearing, balance, taste, smell, voice, speech, and language.

	National Student Speech Language Hearing Association (A)	https://www.nsslha.org	The NSSLHA is a national student organization that is acknowledged by the American Speech-Language-Hearing Association (ASHA). The organization works to motivate and support students in the field through educational research, leadership opportunities, funding, and additional resources.
Glaucoma	NIH – Glaucoma (G)	https://www.nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/glaucoma	This page provides information on glaucoma including types, symptoms, risk factors, causes, diagnoses, treatments, research, and additional resources.
	The Glaucoma Foundation (A)	https://glaucomafoundation.org/	TGF strives to discover a cure for glaucoma through collaboration and comprehensive research. TGF is a non-profit organization that works to educate the public on glaucoma and enhance treatments for patients.
Retinal Detachment and Defects	NIH – Retinal Detachment (G)	https://www.nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/retinal-detachment	This page provides information on retinal detachment including symptoms, risk factors, causes, diagnoses, treatments, research, and additional resources.
	American Society of Retina Specialists (A)	https://www.asrs.org/content/documents/fact-sheet-4-lp-retinal-detachment-r2.pdf	ASRS is a retinal organization that serves as an advocate and source of comprehensive information and education on conditions such as retinal detachment. The organization works to advance access to and quality of care for patients. This page from the organization provides information on retinal detachment.

EMOTIONAL DISTURBANCE			
Anxiety Disorders (Obsessive Compulsive Disorder, Panic Disorder, Phobias, Separation Anxiety Disorder)	NIH – Anxiety Disorders (G)	https://www.nimh.nih.gov/health/topics/anxiety-disorders/index.shtml	This page provides an overview of anxiety disorders including signs and symptoms for each disorder, risk factors, treatments and therapies, current research, and additional resources.
	National Alliance on Mental Illness (A)	https://www.nami.org/About-Mental-Illness/Mental-Health-Conditions/Anxiety-Disorders	NAMI is the nation’s biggest grassroots mental health organization committed to improving the lives of those impacted by mental illnesses such as anxiety disorders. This page provides specific information on anxiety disorders (and others) such as phobias and panic disorder.
Behavioral Disorders (Conduct Disorder, Oppositional Defiant Disorder, Intermittent Explosive Disorder)	CDC – Behavior or Conduct Problems (G)	https://www.cdc.gov/childrensmentalhealth/behavior.html	This page provides information on behavioral problems in children such as oppositional defiant disorder and conduct disorder as well as symptoms, treatment, and additional resources.
	The Child Mind Institute (A)	https://childmind.org/center/adhd-and-behavior-disorders-center/	The Child Mind Institute is a non-profit organization dedicated to supporting children and families struggling with mental health issues such as behavioral disorders. The institute works to improve treatments and care, advance research, and empower communities to support children. This page provides information and resources for behavior disorders such as oppositional defiant disorder, conduct disorder, and intermittent explosive disorder.

Feeding and Eating Disorders (Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder)	NIH – Eating Disorders (G)	https://www.nimh.nih.gov/health/topics/eating-disorders/index.shtml	This page provides information on eating disorders including signs and symptoms, risk factors, treatments and therapies, research, and additional resources.
	National Eating Disorders Association (A)	https://www.nationaleatingdisorders.org/	NEDA is a nonprofit organization that serves to support individuals and families impacted by eating disorders through prevention work, research, and access to quality care. NEDA is comprised of parents, philanthropists, business leaders, and medical professionals who support the goals of the organization.
Mood Disorders (Bipolar Disorder, Cyclothymic Disorder, Depressive Disorders, Dysthymic Disorder)	NIH – Mood Disorders (G)	https://medlineplus.gov/mooddisorders.html	This page provides an overview of mood disorders including types, treatments, symptoms, related issues, current research, and additional resources.
	Depression and Bipolar Support Alliance (A)	https://www.dbsalliance.org/education/educational-materials/	The DBSA focuses on mood disorders such as depression and bipolar disorder. They provide peer-based, wellness-oriented support services to those who need them. The organization strives to support and educate those with mood disorders while empowering them to live fulfilling lives.
Posttraumatic Stress Disorder (PTSD)	NIH – Post-Traumatic Stress Disorder (G)	https://www.nimh.nih.gov/health/topics/post-traumatic-stress-disorder-ptsd/index.shtml	This page provides information on post-traumatic stress disorder including descriptions, signs and symptoms, risk factors, treatments, current research, and additional resources.

	Mental Health America (A)	https://www.mhanational.org/conditions/post-traumatic-stress-disorder	MHA is a community-based nonprofit committed to serving the needs of those living with mental illness. MHA works to prevent mental illness and promote mental health across communities through education, research, advocacy, and supportive services. This page provides information on post-traumatic stress disorder.
Schizophrenia and Other Psychotic Disorders	NIH – Psychotic Disorders (G)	https://medlineplus.gov/psychoticdisorders.html	This page provides information on psychotic disorders such as schizophrenia and includes descriptions, diagnoses and tests, treatments and therapies, genetics, related issues, current research, and additional resources.
	Schizophrenia and Related Disorders Alliance of America (A)	https://sardaa.org/	SARDAA works to support those who live with schizophrenia and related disorders. SARDAA carries out this mission through support programs, education, and advocacy. The Schizophrenia Alliance (SA) is a self-help and peer support program within SARDAA that served those with schizophrenia and related illnesses.
Substance Abuse	Substance Abuse and Mental Health Services Administration (G)	https://www.samhsa.gov/sites/default/files/alcohol-use-facts-resources-fact-sheet.pdf	Substance Abuse and Mental Health Services Administration (SAMHSA) provides a facts and resources document pertaining to alcohol use. This page includes indicators of risky or excessive drinking, an alcohol use screening tool, tips for cutting down on drinking, and a treatment locator.
	Alcoholics Anonymous (A)	https://www.aa.org	A.A. is a nonprofessional, self-supporting, international association of individuals who have had a drinking problem. A.A. offers opportunities for members to tell their stories, receive and provide sponsorship, and follow a Twelve Step program.

MEDICAL CONDITION			
Acquired Immuno-deficiency Syndrome (AIDS)/Human Immuno-deficiency Virus (HIV)	NIH – HIV/AIDS (G)	https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/19/45/hiv-aids--the-basics	This page provides information on HIV and AIDS including key points, transmission, risk factors, treatment, symptoms, diagnoses, and additional resources.
	AIDS Vaccine Advocacy Coalition (A)	https://www.avac.org/	AVAC was created to advance the development of preventive HIV vaccines. This nonprofit organization focuses on research to create long-term solutions, education about HIV/AIDS as well as patient advocacy, and community engagement.
Asthma	CDC – Asthma (G)	https://www.cdc.gov/asthma/default.htm	This page provides information on asthma including descriptions, symptoms, research, emergency care, and interactions with COVID-19.
	Asthma and Allergy Foundation of America (A)	https://www.aafa.org/	AAFA is a non-profit organization founded to support individuals living with asthma through education, advocacy, and research.
Cancers	NIH – National Cancer Institute (G)	https://www.cancer.gov/	This page on the National Cancer Institute website provides information on cancer including causes and prevention, diagnosis and staging, prognosis, treatment side effects, and additional resources.
	American Cancer Society (A)	https://www.cancer.org/cancer.html	The American Cancer Society is a national community-based voluntary health institution committed to eliminating cancers. The organization carries out their mission through encouraging prevention, advocating with lawmakers, increasing access to care, funding and conducting research, and supporting multicultural communities to help reduce cancer risk.

Chronic Granulomatous Disease	NIH – Chronic Granulomatous disease (G)	https://ghr.nlm.nih.gov/condition/chronic-granulomatous-disease	This page provides information on chronic granulomatous disease including descriptions, causes, inheritance patterns, diagnoses and management, and additional resources.
	Immune Deficiency Foundation (A)	https://primaryimmune.org/about-primary-immunodeficiencies/specific-disease-types/chronic-granulomatous-disease-and-other-phagocytic-cell-disorders/	The IDF works to improve the treatment and quality of life of those impacted by primary immunodeficiency. The foundation uses advocacy, education, and research to support these communities and addresses patient needs through public policy programs. This page provides information on chronic granulomatous disease and other phagocytic cell disorders.
Congenital Cystic Lung	NCBI – Congenital Cystic Lung Diseases (G)	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3625881/	This article provides information on congenital cystic lung diseases including types, symptoms, diagnoses, and additional research.
	American Lung Association (A)	https://www.lung.org/lung-health-diseases/lung-disease-lookup	The American Lung Association is an organization that employs education, research, and advocacy to improve lung health and prevent lung disease in communities across the country. The association's main objectives are to eliminate lung cancer, advocate for cleaner air, improve the well-being of those with lung diseases, and work towards a tobacco-free environment. This page provides information on a range of lung diseases.
Congenital Heart Defects	CDC – Congenital Heart Defects (G)	https://www.cdc.gov/ncbddd/heartdefects/facts.html	This page provides information on congenital heart defects including types, signs and symptoms, diagnoses, treatments, causes, research, and additional resources.

	The Children’s Heart Foundation (A)	https://www.childrensheartfoundation.org/about-chds/	The Children’s Heart Foundation is committed to funding congenital heart defect (CHD) research. The foundation serves to advance the diagnosis, prevention, and treatment of CHDs as well as providing education to families and communities.
Crigler-Najjar Syndrome	NIH – Crigler-Najjar Syndrome (G)	https://ghr.nlm.nih.gov/condition/crigler-najjar-syndrome	This page provides information on Crigler-Najjar syndrome including descriptions, frequency, causes, inheritance patterns, diagnosis and management, and additional resources.
	National Organization for Rare Disorders (NORD) – Crigler-Najjar Syndrome (A)	https://rarediseases.org/rare-diseases/crigler-najjar-syndrome/	This organization’s page provides information on Crigler-Najjar syndrome including a general discussion of the syndrome, signs and symptoms, causes, impacted populations, related disorders, diagnosis, standard therapies, investigational therapies, member and general organizations, and additional resources.
Crohn’s Disease	NIH – Crohn’s Disease (G)	https://medlineplus.gov/crohnsdisease.html	This page provides information on Crohn’s disease including diagnoses and tests, treatments and therapies, research, genetics, general information, related issues, and additional resources.
	Crohn’s & Colitis Foundation (A)	https://www.crohnscolitisfoundation.org/	The Crohn’s & Colitis Foundation is a non-profit organization working to find cures for Crohn’s disease and ulcerative colitis as well as improve the quality of life for those impacted by these illnesses. The foundation funds research studies and clinical studies, empowers patients and caregivers, educates health professionals, and collaborates with communities to further their advocacy efforts and support those affected by these diseases.

Cushing's Syndrome	NIH – Cushing's Syndrome (G)	https://www.niddk.nih.gov/health-information/endocrine-diseases/cushings-syndrome	This page provides information on Cushing's Syndrome including prevalence, complications, symptoms, causes, diagnoses, treatments, current research, and additional resources.
	Urology Care Foundation (A)	https://www.urologyhealth.org/urologic-conditions/cushings-syndrome	The Urology Care Foundation works to educate patients and the public using current and comprehensive urologic research. The foundation participates in public awareness campaigns, supports patients living with urological conditions, and provides additional resources to patients.
Cystic Fibrosis	NIH – Cystic Fibrosis (G)	https://ghr.nlm.nih.gov/condition/cystic-fibrosis	This page provides information on cystic fibrosis including descriptions, causes, and management, current research, and additional resources.
	Cystic Fibrosis Foundation (A)	https://www.cff.org/	The Cystic Fibrosis Foundation is a non-profit that is dedicated to curing cystic fibrosis through research and medication development. The foundation works to improve specialized care and provide support to those impacted by CF.
Diabetes and Digestive and Kidney Diseases	National Institute of Diabetes and Digestive and Kidney Diseases (G)	https://www.niddk.nih.gov	National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) supports research and research training at universities and other institutions across the country, conducts research in NIDDK laboratories, coordinates and plans research through meetings and strategic reports, and accelerates research by providing data and samples from NIDDK-funded studies. NIDDK also provides science-based information to patients and their families, health professionals, and the public.

	American Diabetes Association (A)	https://www.diabetes.org/diabetes	The American Diabetes Association provides information about diabetes and resources for those impacted by diabetes. The association provides tools for individuals to assess their risk, find the best treatment and educational programs, and plan meals and exercise routines. The website also provides space for those in the community to share their stories.
Encephalopathy Epilepsy	NIH – Early Infantile Epileptic Encephalopathy (G)	https://rarediseases.info.nih.gov/diseases/9255/early-infantile-epileptic-encephalopathy	This page provides information on epileptic encephalopathy including symptoms, related diseases, organizations, treatments, and additional resources.
	Epilepsy Foundation of America (A)	https://www.epilepsy.com/	The Epilepsy Foundation serves to help and support individuals as they overcome the difficulties of living with epilepsy. The foundation works to find a cure and advance therapies and treatments so that those impacted by epilepsy can improve their quality of life.
Hemophilia/Bleeding Disorders	NIH – Bleeding Disorders (G)	https://www.nlm.nih.gov/health-topics/bleeding-disorders	This page provides information on bleeding disorders including types, causes, risk factors, screening and preventions, symptoms and complications, diagnoses, treatment, research, and additional resources.
	Hemophilia Federation of America (A)	https://www.hemophiliafed.org/advocacy/	The HFA works to advocate for those living with bleeding disorders. This non-profit organization was founded to serve the needs of the bleeding disorders community and push for safe and accessible health coverage and treatment for patients and families.

Hydrocephalus	NIH – Hydrocephalus (G)	https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Hydrocephalus-Fact-Sheet	This page details information on hydrocephalus including types, vulnerable populations, causes, symptoms, diagnoses, treatments, prognoses, research, and additional resources.
	Hydrocephalus Association (A)	https://www.hydroassoc.org/about-us/who-we-are/mission/	The Hydrocephalus Association works to educate the public on hydrocephalus and fund research for a cure. The association connects those impacted by the condition to larger communities. Their mission is to help improve the lives of those impacted by hydrocephalus as they continue their research for a cure and collaborate with community members to increase awareness of the condition.
Hypertension	CDC – Hypertension (G)	https://www.cdc.gov/bloodpressure/facts.htm	This page provides information on hypertension including descriptions, contributing factors, prevalence rates, and additional resources.
	American Heart Association (A)	https://www.heart.org/en/about-us	The American Heart Association was founded by a group of cardiologists in 1924. The AHA is a voluntary organization built to fight stroke and heart disease and support patients' cardiovascular health.
Lead Poisoning	CDC – Prevent Children's Exposure to Lead (G)	https://www.cdc.gov/nceh/features/leadpoisoning/index.html	This page provides information on preventing lead exposure in children including lead hazards, health consequences, treatment, and additional resources.

	American Academy of Pediatrics (A)	https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/lead-exposure/Pages/Lead-Exposure-in-Children.aspx	The AAP is an organization of pediatricians dedicated to providing resources and information to support the optimal health of all children and adults. This page provides information on lead exposure in children.
Leukemia	NIH – Leukemia (G)	https://www.cancer.gov/types/leukemia	This page details information on leukemia for patients including overviews, treatments, causes and prevention, screening, research, statistics, and additional resources.
	The Leukemia & Lymphoma Society (A)	https://www.lls.org/leukemia	LLS works to cure leukemia and related diseases as well as support patients and families. LLS funds extensive research and provides information, resources, and services to patients.
Liver Disease	NIH – Liver Disease (G)	https://www.niddk.nih.gov/about-niddk/research-areas/liver-disease	This page provides information on liver disease including definitions and descriptions as well as news and updates on liver disease research.
	American Liver Foundation (A)	https://liverfoundation.org	The American Liver Foundation works to educate the public on liver disease, advocate for and support those living with liver disease, and conduct research on treatment and prevention.
Lupus	CDC – Lupus (G)	https://www.cdc.gov/lupus/index.htm	This page provides information on lupus including symptoms, treatment, research, and additional resources.
	Lupus Foundation of America (A)	https://www.lupus.org/about-us	The Lupus Foundation of America implements programs of education, research, advocacy, and improve the quality of life for those impacted by lupus. Members work to provide patients with timely diagnoses and access to treatment.

Metabolic Disorders	MedlinePlus – Metabolic Disorders (G)	https://medlineplus.gov/metabolicdisorders.html	This page provides information on metabolic disorders including diagnoses and tests, details on specific disorders, genetics, clinical trials, journal articles, expert and patient resources.
	Children’s National Rare Disease Institute (A)	https://childrensnational.org/departments/rare-disease-institute	Children’s National Rare Disease Institute (CNRDI) aims to advance the care and treatment of individuals with rare genetic diseases, including metabolic diseases. CNRDI provides a medical home for those in need of care and expertise for rare genetic conditions. This division arranges multidisciplinary care for children with metabolic, genetic, and undiagnosed disorders.
Microcephaly	CDC – Microcephaly (G)	https://www.cdc.gov/ncbddd/birthdefects/microcephaly.html	This page details information on microcephaly including definitions, severity, corresponding problems, symptoms, prevalence, causes, risk factors, diagnoses, treatments, and additional resources.
	Child Neurology Foundation (A)	https://www.childneurologyfoundation.org/disorder/microcephaly/	The Child Neurology Foundation aims to support children impacted by neurological disorders and act as a collaborative source of education for families. This page on the foundation’s website details information on microcephaly and corresponding organizations.
Nutritional Deficiency	NCBI – Nutrition in Children (G)	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3607807/	This article discusses the role of nutrition in children’s neurocognitive development.

	American Society for Nutrition (A)	https://nutrition.org/	The ASN was founded to advance research, education, and practice of nutrition across communities.
Pancreatic Disease	NIH – Pancreatitis (G)	https://www.niddk.nih.gov/health-information/digestive-diseases/pancreatitis	This page provides information on pancreatitis including definitions, symptoms, causes, diagnoses, treatments, and additional resources.
	The National Pancreas Foundation (A)	https://pancreasfoundation.org/patient-information/about-the-pancreas/common-disorders-of-the-pancreas/	The National Pancreas Foundation supports those suffering from pancreas conditions through funding research, advocating for better treatment, and providing education to patients, families, clinicians, and the general public.
Pollution-Related Illnesses	NCBI – Effects of Air Pollution on the Health of Children (G)	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2528642/	This article details information on the pediatric health consequences of air pollution including mortality outcomes, adverse pregnancy outcomes, birth defect risks, adverse respiratory health outcomes, and additional data and resources.
	Our Children’s Earth Foundation (A)	https://www.ocefoundation.org/	Our Children’s Earth Foundation is a non-profit organization dedicated to promoting public awareness of human rights issues and environmental impacts through education and research. The foundation empowers communities to take action and advocates for children to ensure they are living in a clean environment.
Sarcomas	NIH – Soft Tissue Sarcoma (G)	https://www.cancer.gov/types/soft-tissue-sarcoma	This page provides information on soft tissue sarcoma including symptoms, diagnoses, treatments, and additional resources.

	Sarcoma Alliance (A)	https://sarcomaalliance.org/	The Sarcoma Alliance serves to support those impacted by sarcoma through education, comprehensive diagnoses, and access to quality care.
Sickle Cell Anemia	CDC – Sickle Cell Disease (G)	https://www.cdc.gov/ncbddd/sicklecell/index.html	This page provides information on sickle cell disease including symptoms, diagnoses, treatments, and additional resources.
	Sickle Cell Disease Association of America (A)	https://www.sicklecelldisease.org/	The mission of the SCDA is to advocate for those impacted by sickle cell conditions and both promote and advance initiatives targeting sickle cell diseases.