



If you're holding this notebook it's likely you just received the news that your child is a pediatric stroke survivor. There's a good chance that your world is spinning right now and you might be feeling completely overwhelmed. We've been in your shoes and want to help make things a little less crazy where we can! That's why we made this Care Notebook especially for you. This is a place to keep all of the important information regarding your child. There are a handful of forms with plenty of space for you to keep track of appointments, medications, etc. It also includes a zip drive to hold anything you'd like to download and have on hand, a pouch to keep a pen and any discs you may receive and a couple of folders to hold important paperwork or receipts.

However, out of all the things in this notebook, the most important one is right up front, **support information!** This has our contact information plus multiple websites that will be great resources for you., as they have been for us.

One of our main priorities at the Children's Stroke Foundation is to make sure all survivor families feel supported and never alone. So please reach out to us if you need anything. We've been there!! Please remember that no matter what you've been told or what scans you have seen, they do not define your child. Those scans do not dictate your child's capabilities. Stay strong and know that there is hope and know your child will surprise you everyday.

Early intervention is key so I would urge you to get in contact with your local infant and toddler services or specialists as soon as possible. Get in touch with us and we can help put you in contact with other families in your area. You are not alone!

- Shiloh Little and Sara Mitchell
Co-founders Children's Stroke Foundation
of the Midwest

Support Resources

Support Group or Organization	
Contact Person	
Address:	
Website/Email:	
Phone:	
Fax:	

Support Group or Organization	
Contact Person	
Address:	
Website/Email:	
Phone:	
Fax:	

Children's Stroke Foundation of the Midwest

Shiloh Little and Sara Mitchell

22754 W 220 St. Spring Hill KS 66083

kidscanhavestrokestoogmail.com

(913)940-0089

Therapy Locations

PossAbilities Children's Therapy Group

Speech, Physical and Occupational
Therapy

www.poss-abilities.com

913-620-1007

Beyond Function

Occupational Therapy

www.beyondfunctionllc.com

913-515-6298

Bringing Therapy Home

Speech Therapy, Occupational Therapy,
Feeding Therapy, Music Therapy

www.bringingtherapyhome.com

913-754-6643

Therapy in Motion

Physical Therapy

www.Therapyinmotionkc.com

816-547-9654

Children's Therapy Services

Speech and Occupational Therapy

www.childrenstherapycts.com

913-912-2174

Children's Physical Therapy Associates

Land and Aquatic Physical Therapy

www.ptr4kids.com

913-345-1997

Playabilities

Occupational, Physical, Speech Therapy

www.playabilities.org

913-213-3531

New Horizons Ranch

Therapeutic Horseback Riding

www.newhorizonranch.org

913- 620-2788

Northland Therapeutic Riding Center

Therapeutic Horseback Riding

813-808-1106

LeAnn Brittan IDC

www.brittancenter.org

913-676-2253

Children's Mercy Hospital

www.childrensmercy.org

816-234-3000

Easterseals Capper Foundation

www.easterseals.com/capper

785-272-4060

TARC

www.tarcinc.org

785-232-0597

Overland Park Regional Medical Center

913-541-5562

Early Childhood (birth-3)

Johnson County Infant/Toddler

www.itsjc.org

913-432-2900

Missouri First Steps

www.mofirststeps.com

Also check with your county/city/school district for Parents as Teachers or other local early intervention services.

Sports and Other Activities

I can Bike

www.icanbike.org

Midwest Adaptive Sports

Various Activities

www.midwestadaptivesports.org

Baseball/Kickball

www.olatheks.org/parksrec

Miracle League

913-917-8563

SOAR at Grace Church

Support group, respite care nights, summer day camps

<https://visitgracechurch.com/soar/>

Adaptive Dance

Kansas City Ballet

www.kcballet.org/school

816-931-2299

All Abilities Cheer

Team Inspire

kcac@kacaccheer.com

Challenge Air

www.challengeair.org

214-351-3353

Challenge Games

Adaptive Track and Field

www.challengegames.org

TEAM Soccer

<https://www.sportingbvssoccer.org/team-soccer>

Constraint Therapy Camps

Ability KC

816-751-7710

PossAbilities Children's Therapy Group

www.poss-abilities.com

913-620-1007

Additional Camps

Wild Wilderness Kids

Therapeutic Nature Center

www.wellwildernesskids.com

913-281-8581

Special Needs Financial Resources

Local:

John Gantzer- Edward Jones

(913) 469-0290

www.edwardjones.com/john-gantzer

Kacy Seitz - Northwestern Mutual

kacy.seitz@nm.com

816-412-1515

Deborah Niemann- Northwestern Mutual

816-506-0884

National:

Falling Forward Foundation

www.fallingforward.org

785-550-8129

Alyssa V. Phillips Foundation

<https://www.alyssavphillipsfoundation.com/>

CHASA (Children's Hemiplegia and Stroke Association)

<http://chasa.org/>

The Laney Jaymes Foundation Adaptive Equipment Grant

<http://www.laneyjaymes.org/who-we-support>

United Healthcare Children's Foundation

<http://www.uhccf.org/>

Providers

Dr. Marcie Files- CMH

Pediatric Neurologist - Stroke Specialty

816-234-3000

Dr. Jennifer Prohaska - CMH

Neuropsychologist

913-588-6400

Dr. Nicole McCarten- CMH

Rehab

816-234-3970

Dr. Ganesh Gupta

Pediatric Orthopedic Associates

913-451-0000

<https://www.pedorthokc.com/>

Dr. Laura Plummer- CMH

Ophthalmologist

816-960-8000

Dr. Brian Aalbers - OPRMC

Pediatric Neurologist

913-599-3828

Dr. Katherine Burns - OPRMC

Developmental Pediatrician

913-541-5022

Dr Robert Beatty - OPRMC

Neurosurgeon

913-541-5500

Children's Center for the Visually Impaired

Visual Processing Evaluations

<https://ccvi.org/>

816- 841-2284

Neuropsychological Testing

Children's Mercy

816-234-3674

Sunflower Vision Development Center

In depth evaluation of vision and processing

913-631-0262

Other Local Resources

Brain Injury Association of Kansas

<http://biaks.org>

Variety – The Children's Charity of Greater Kansas City

<http://varietykc.org>

National Online Resources

Accessible Playground

www.p2pusa.org/parents/

CampResource

www.campresource.com/

Child Neurology Foundation

www.childneurologyfoundation.org

Inspired by Pediatrics

<https://inspiredbypediatrics.com/>

Kids' Waivers

www.kidswaivers.org/

Parent to Parent USA

www.p2pusa.org/parents/

Understood

www.understood.org/en.

Bright Spot Pediatric Stroke

<https://www.facebook.com/brightspotps/>

Getting to Know Me

My Name:	Nickname:
Birthdate:	Today's Date:
A little about me:	
My strengths (things that are easy for me):	
My challenges (communication, feeding, learning, mobility, social, energy, behavior...):	
Places I spend time (school, childcare, place of worship, special places):	
Ways you can be helpful to me:	
Things to avoid (food, activities, procedures...):	
My equipment/assistive technology:	
Other:	

Medical Summary

Allergies/Sensitivities	Reaction	Allergies/Sensitivities	Reaction

Healthcare and Other Providers

Primary Care Provider:	Phone:
Specialty Provider:	Phone:
Other provider:	Phone:
Other Provider:	Phone:
Other Provider:	Phone:

Medical Equipment	Medical Supplies	Provider	Contact Info

Immunization History (Date(s))

Influenza:	Hepatitis b:	MME:	Meningococcus:
Tdap:	Hepatitis A:	Varicella:	Polio:
PPD:	Pneumovax:	HPV:	

Health Insurance

Name:	Name:
Group #:	Group #:
ID#:	ID#:
Phone:	Phone:

Other important info:

Hospital and Clinic Information

Medical Record Number: _____

Hospital Address: _____

City, State, Zip Code: _____

Website: _____

Phone Numbers: _____

Specialty Clinic Name:	Specialty Clinic Name:
Hours/Days of Operations:	Hours/Days of Operations:
Physician:	Physician:
Contact Person:	Contact Person:
Phone:	Phone:
Email:	Email:
Fax:	Fax:
Specialty Clinic Name:	Specialty Clinic Name:
Hours/Days of Operations:	Hours/Days of Operations:
Physician:	Physician:
Contact Person:	Contact Person:
Phone:	Phone:
Email:	Email:
Fax:	Fax:

Care Provider:	Care Provider:
Name:	Name:
Phone:	Phone:
Fax:	Fax:
Start Date:	Start Date:
End Date:	End Date:
Address:	Address:
Email:	Email:
Website:	Website:
Care Provider:	Care Provider:
Name:	Name:
Phone:	Phone:
Fax:	Fax:
Start Date:	Start Date:
End Date:	End Date:
Address:	Address:
Email:	Email:
Website:	Website:
Care Provider:	Care Provider:
Name:	Name:
Phone:	Phone:
Fax:	Fax:
Start Date:	Start Date:
End Date:	End Date:
Address:	Address:
Email:	Email:
Website:	Website:

