



**Supportive  
and Bereavement  
Resources Directory  
for Southwestern  
Pennsylvania**

For families, volunteers and medical professionals caring for children with life-limiting illnesses.



*Working together for medically fragile children.*

# Welcome

## **Our Mission:**

To provide resources to families, volunteers and medical professionals caring for children with life-limiting illnesses.

We hope this resource directory can help you with whatever situation you are facing. You may have learned your child or newborn has a serious or life-threatening illness or condition and want more information. You may have been caring for a very ill child for a long while and need some relief or respite. You may be grieving the loss of a child. Or you may be a professional in search of additional resources.

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.\*

It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress.

Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centers and even in children's homes.

\* *World Health Organization (WHO) Definition of Palliative Care for Children (WHO; 1998a)*

# Supportive Resources

## Hospitals

### **Allegheny General Hospital/ West Penn Allegheny Health System**

320 E. North Avenue  
Pittsburgh, PA 15212  
412.359.3131  
[www.wpahs.org](http://www.wpahs.org)

### **Children's Hospital of Pittsburgh of UPMC**

4401 Penn Avenue  
Pittsburgh, PA 15224  
412.692.5325  
[www.chp.edu](http://www.chp.edu)

### **The Children's Institute**

1405 Shady Avenue  
Pittsburgh, PA 15217  
412.420.2400  
[www.amazingkids.org](http://www.amazingkids.org)

### **Magee-Womens Hospital of UPMC**

300 Halket Street  
Pittsburgh, PA 15213  
412.641.1000;  
NICU Secretary 412.641.4585  
[www.magee.edu](http://www.magee.edu)

### **Pediatric Specialty Hospital**

The Children's Home  
& Lemieux Family Center  
5324 Penn Avenue  
Pittsburgh, PA 15224  
412.441.0700  
[www.childrenshomepgh.org](http://www.childrenshomepgh.org)

### **West Penn Pediatrics Department/ West Penn Allegheny Health System**

4800 Friendship Avenue  
Pittsburgh, PA 15224  
412.578.5000  
[www.wpahs.org](http://www.wpahs.org)

## Home Health Care Services

### **Bayada Nurses – Pediatric Office**

300 Oxford Drive, Suite 410  
Pittsburgh, PA 15146  
412.374.0110/1.877.412.8950  
[www.bayadanurses.com](http://www.bayadanurses.com)

### **Care Unlimited, Inc.**

3288 Babcock Boulevard  
Pittsburgh, PA 15237  
412.367.3620/1.800.535.3747  
[www.careunlimitedinc.com](http://www.careunlimitedinc.com)

### **Conemaugh Home Health**

130 W. Osbourne Street  
Johnstown, PA 15905  
814.534.9150  
[www.conemaugh.org](http://www.conemaugh.org)

### **Extended Family Care**

10 Duff Road, Suite 407  
Pittsburgh, PA 15235  
412.241.7292  
[www.starmulticare.com](http://www.starmulticare.com)

### **Interim Healthcare, Inc.**

1789 S. Braddock, Suite 220  
Pittsburgh, PA 15218  
412.436.2200/1.800.447.2030  
[www.interim-health.com](http://www.interim-health.com)

### **Loving Care Agency of Pittsburgh**

875 Greentree Road  
Building #3, Suite 325  
Pittsburgh, PA 15220  
412.922.3435  
[www.lovingcareagency.com](http://www.lovingcareagency.com)

### **PSA Healthcare**

1501 Reedsdale Street, Suite 4002  
Pittsburgh, PA 15233  
412.322.4140/1.800.331.1916  
[www.psakids.com](http://www.psakids.com)

## Family-Centered Medical Care

### **Squirrel Hill Health Center**

200 JHF Drive  
Pittsburgh, PA 15217  
412.904.5283  
[www.squirrelhillhealthcenter.org](http://www.squirrelhillhealthcenter.org)

## Pediatric Hospice Care

### **Connemaugh Regional Hospice**

315 Locust Street, Suite 5E  
Johnstown, PA 15901  
814.534.6100  
[www.connemaugh.org](http://www.connemaugh.org)

### **Family Hospice and Palliative Care Karing for Kids**

50 Moffet Street  
Pittsburgh, PA 15243  
412.572.8800  
[www.familyhospice.com](http://www.familyhospice.com)

### **Fayette Home Care and Hospice**

110 Youngstown Road  
Lemont Furnace, PA 15456  
724.439.1610  
[www.fayettehomecare.net](http://www.fayettehomecare.net)

### **Forbes Hospice Children's Services**

115 S. Neville Street  
Pittsburgh, PA 15213  
412.325.7200  
[www.forbeshospice.org](http://www.forbeshospice.org)

### **Great Lake Home Healthcare and Hospice**

1700 Peach Street, Suite 244  
Erie, PA 16501  
814.877.6120  
[www.hammot.org](http://www.hammot.org)

### **In Touch Hospice**

1474 N. Center Avenue  
Somerset, PA 15501  
814.443.5047  
[somersehospitalhomehealth.com/in](http://somersehospitalhomehealth.com/in)  
[www.touch.htm](http://www.touch.htm)

### **Three Rivers Hospice**

1195 Jack's Run Road  
N. Versailles, PA 15137  
412.349.0760  
[www.threerivershospice.org](http://www.threerivershospice.org)

### **Valley Hospice, Inc.**

308 Mt. St. Joseph Road  
Wheeling, WV 26003  
304.242.1977  
[www.valleyhospice.org](http://www.valleyhospice.org)

### **Valley Hospice, Inc.**

10686 State Route 150  
Steubenville, Ohio 43952  
1.877.467.7423  
www.valleyhospice.org

### **Vitas® Innovative Hospice Care/Vitas Palliative Care Solutions**

235 Alpha Drive, Suite 101  
Pittsburgh, PA 15238  
1.800.865.7153  
www.vitas.com

### **VNA Hospice of W. Pennsylvania**

154 Hindman Road  
Butler, PA 16001  
724.282.6806/1.877.862.6659

806 West Main Street  
Grove City, PA  
724.458.4410  
www.vna.com

## **Daycare and Respite Services**

### **Alliance for Community Respite Care (now UCP/CLASS)**

4638 Centre Avenue  
Pittsburgh, PA 15213

1400 S. Braddock Avenue  
Pittsburgh, PA 15218  
412.683.7100/1.888.954.2424  
info@ucpclass.org  
www.ucpclass.org

### **Care Break – The Watson Institute**

301 Camp Meeting Road  
Sewickley, PA 15143  
412.749.2863  
www.thewatsoninstitute.org

### **Children's Institute Day School and Children's Institute Respite Care**

1405 Shady Avenue  
Pittsburgh, PA 15217  
412.420.2400/1.877.433.1109  
www.amazingkids.org

### **Child's Way – The Children's Home and Lemieux Family Center**

5324 Penn Avenue  
Pittsburgh, PA 15224  
412.441.0700  
www.childrenshomepgh.org

### **Spina Bifida Association of W. Pennsylvania**

1158 Dutilh Road  
Mars, PA 16046  
724.934.9600/1.800.243.5787  
www.sbawp.org

## **Recreation**

### **Lighthouse Family Retreat**

(Free weeklong family seaside vacations in FL for kids with cancer)  
www.lighthousefamilyretreat.org

### **Make-A-Wish Foundation of Greater PA and Southern WV**

707 Grant Street, 37th Floor  
Pittsburgh, PA 15219  
412.471.9474/1.800.676.9474  
www.wishgreaterpa.org

### **The Bill Neches Heart Camp for Kids**

Annual Heart Center Family Picnic  
Heart Center of Children's Hospital of Pittsburgh of UPMC  
www.chp.edu

### **The Woodlands Foundation Camp**

134 Shenot Road  
Wexford, PA 15090  
724.935.6533  
www.woodlandsfoundation.org

## **Family Housing**

### **McKee Family House**

5301 Fifth Avenue  
Pittsburgh, PA 15232  
412.647.7777 (Hotline)  
www.familyhouse.org

### **Ronald McDonald House**

451 44th Street, Penthouse  
Pittsburgh, PA 15201  
412.362.3400  
www.rmhcpggh.org

## **Non-Medical Support**

**Achieva** (Early intervention services provider for children with special needs)  
www.achieva.org

### **Caring Companions** (housekeeping)

Box 4352, New Kensington, PA 15068  
724.337.7581  
Box 476, Youngwood, PA 15697  
www.stayathomecare.net

### **Early Learning Institute**

2510 Baldwin Road  
Pittsburgh, PA 15205  
412.922.8322  
www.telipa.org

### **East End Cooperative Ministry**

250 N. Highland Avenue  
Pittsburgh, PA 15206  
412.361.5549  
www.eecm.org

### **Every Child, Inc.** (care coordination)

6401 Penn Avenue  
Pittsburgh, PA 15206  
412.665.0600  
www.everychildinc.org

### **Food Emergencies**

- East End Cooperative Ministry  
412.361.5549
- Greater pittsburgh Community Food Bank  
412.460.3663
- Hunger Services Network  
412.681.1121

### **MassMutual Special Care**

GuyauxMandlerMah Financial Group  
hsims@finsvcs.com  
www.massmutual.com/specialcare

### **Mended Little Hearts**

(support for families of children with heart defects and heart disease)  
507 Baughman Avenue  
Jeannette, PA 15644  
724.396.7820  
www.swpa.mendedlittlehearts.net

### **Neighborhood Legal Services**

928 Penn Avenue  
Pittsburgh, PA 15222  
412.255.6700  
1.866.761.6572  
www.nlsa.us

### **Parent Resource Network**

(Outreach services to families with children born prematurely with chronic illness and/or congenital disorders.)

5151 Penn Avenue,  
Pittsburgh, PA 15224  
1.877.647.4373  
[www.parentresourcenetwork.org](http://www.parentresourcenetwork.org)

### **Partnership for Parents**

(Online support service created by parents, for parents of children with serious illnesses.)

[www.partnershipforparents.org](http://www.partnershipforparents.org)

### **Pitt School of Law Health Law Clinic**

412.648.1300

### **Romano, Joseph, Attorney**

1.800.331.4134  
[www.josephromanolaw.com](http://www.josephromanolaw.com)

### **Disease Specific Organizations**

These organizations are non-profit agencies that offer education, emotional support, financial assistance, research support and other resources to families and caregivers.

### **Alliance of Genetic Support Groups**

[www.geneticalliance.org](http://www.geneticalliance.org)

### **American Lung Association of W PA**

1.800.586.4872

### **Brain Tumor Foundation for Children**

1.404.252.4107  
[www.braintumorkids.org](http://www.braintumorkids.org)  
email: [btfc@bellsouth.net](mailto:btfc@bellsouth.net)

### **Cancer Caring Center**

4117 Liberty Avenue  
Pittsburgh, PA 15224  
412.622.1212  
[www.cancercaring.org](http://www.cancercaring.org)

### **Children's Organ Transplant Association**

1.800.366.2682  
[www.cota.org](http://www.cota.org)

### **Children's Sickle Cell Foundation**

226 Paul Street, Suite 105  
Pittsburgh, PA 15211  
412.488.2723  
[www.cscfkids.org](http://www.cscfkids.org)

### **Cystic Fibrosis Foundation**

1.800.344.4823  
[www.cff.org](http://www.cff.org)

### **Elizabeth Glaser Pediatric AIDS Foundation**

1.888.499.4673  
[www.pedaids.org](http://www.pedaids.org)

### **Gilda's Club**

2816 Smallman Street,  
Pittsburgh, PA 15222  
412.338.1919  
[www.gildasclubwesternpa.org](http://www.gildasclubwesternpa.org)

### **Heart to Heart Support Group – Children's Hospital of Pittsburgh of UPMC**

[www.chp.edu](http://www.chp.edu)

### **Juvenile Diabetes Research Foundation – W PA Chapter**

412.471.1414

### **Leukemia and Lymphoma Society**

412.395.2873  
[www.leukemia-lymphoma.org](http://www.leukemia-lymphoma.org)

### **Liver Families (Pediatric liver disease)**

[www.liverfamilies.net](http://www.liverfamilies.net)

### **March of Dimes**

650 Smithfield Street, Suite 1180  
Pittsburgh, PA 15222  
412.391.3193  
[www.marchofdimes.com](http://www.marchofdimes.com)

### **Muscular Dystrophy Association**

1.800.572.1717  
[www.mdausa.org](http://www.mdausa.org)

### **National Health Information Center**

1.800.336.4797  
[www.health.gov/nhic](http://www.health.gov/nhic)

### **National Kidney Foundation**

3109 Forbes Avenue  
Pittsburgh, PA 15213  
412.261.4115/1.800.622.9010  
[www.kidney.org](http://www.kidney.org)

### **National Organization for Rare Disorders**

1.800.999.6673  
[www.rarediseases.org](http://www.rarediseases.org)

### **Osteogenesis Imperfecta Foundation**

[www.oif.org](http://www.oif.org)

### **Parent's Resource Network – Perinatal Palliative Care**

1.877.647.4373 #707  
[ppc@parentresourcenetwork.org](mailto:ppc@parentresourcenetwork.org)

### **St. Jude's Children's Research Hospital**

1.866.278.5833  
[www.stjude.org](http://www.stjude.org)

### **Spina Bifida Association of W PA**

1.800.243.5787  
[www.sbawp.org](http://www.sbawp.org)

### **Support Organization for Trisomies**

(Downs Syndrome, Trisomy 13, 18, and others)  
1.800.716.7638  
[www.trisomy.org](http://www.trisomy.org)

### **United Mitochondrial Disease Foundation**

412.793.8077/1.888.317.8633  
[www.umdf.org](http://www.umdf.org)

### **Message Centers/Care Pages**

Online centers for parents to keep family and friends informed about their child's progress.

### **Beyond Indigo**

[www.beyondindigo.com](http://www.beyondindigo.com)

### **CarePages – Children's Hospital of Pittsburgh of UPMC**

[www.CarePages.com](http://www.CarePages.com)

### **CaringBridge™**

[www.caringbridge.com](http://www.caringbridge.com)

## Local Telephone Hotlines

### Parent Resource Network Hotline

(Parent volunteers 9am-9pm sharing information and offering support for babies born prematurely, with chronic illness and/or birth defects.)  
1.877.647.4373

### United Way Help Line

(Staffed by professional counselors, this information and referral center deals with health care, social services and self-help groups in Allegheny County.)  
412.255.1155  
www.unitedwaypittsburgh.org

## Bereavement Resources

## Local Bereavement Resources

### Camp Good Sam, Camp Erin

(Camps for kids who have lost a family member.)  
www.good-samaritanhospice.org

### Candlelighters Childhood Cancer Foundation of W PA

814 Wainwright Drive  
Pittsburgh, PA 15228  
412.561.5211  
www.candle.org

### Catholic Charities – Allegheny County

212 Ninth Street  
Pittsburgh, PA 15222  
412.456.6975 (Referral)

### The Compassionate Friends

PO Box 17388  
Pittsburgh, PA 15235  
412.835.1105  
www.compassionatefriends.org  
www.tcfpittsburgh.org

### Flashes of Hope

(Free photography of your ill child)  
www.flashesofhope.org

### The Good Grief Center for Bereavement Support

2717 Murray Avenue  
Pittsburgh, PA 15217  
412.224.4700/1.888.GRIEF88  
www.goodgriefcenter.com

### Highmark Caring Place

A Center for Grieving Children, Adolescents and their Families  
620 Stanwix Street  
Pittsburgh, PA 15222  
1.888.224.4673  
www.highmarkcaringplace.com

### Now I Lay Me Down To Sleep

(Photography to memorialize your baby)  
www.nowilaymedowntosleep.org

### Pittsburgh Muslim Family Support Services

424 West Grant Avenue  
Duquesne, PA 15110  
412.612.6381 (Riffat S. Chughtai)  
www.pmfss.org

### The Pittsburgh Pastoral Institute

6324 Marchand Street  
Pittsburgh, PA 15206  
412.661.1239

### SIDS of PA/Cribs for Kids

810 River Avenue, Suite 250  
Riverfront Place, Pittsburgh, PA 15215  
412.322.5680/1.800.721.7437  
www.sids.pa.org

## Internet Grief Resources

### Baby Steps

www.babysteps.com

### Before Their Time

www.beforetheirtime.org

### Center for Loss and Life Transition

www.centerforloss.com

### Compassionate Passages, Inc.

www.compassionatepassages.org

### Compassion Books

www.compassionbooks.com

### GriefNet

www.griefnet.org

### Grieving.com

www.forums.grieving.com

### Healing Hearts for Bereaved Parents

www.healingheart.net

### KIDSAID

www.kidsaid.com

### MEND

(Mothers Enduring Neonatal Death)  
www.mend.org

### MISS Foundation

(Mothers in Sympathy and Support)  
www.missfoundation.org

### A Place to Remember

1.800.631.0973  
www.aplacetoremember.com

### SIDS of PA/Cribs for Kids

www.sids-pa.org

## Memorials

### The Centering Corporation

402.553.1200  
www.centering.org

### David Pegher Portraits

www.aplacetoremember.com  
email: aptr@aplacetoremember.com

### MISS Foundation

623.979.1000  
www.missfoundation.org  
Local contact: Kym Smith,  
Kym@missfoundation.org

### A Place to Remember

1.800.631.0973  
www.aplacetoremember.com

## Organ Donation CORE

(Center for Organ Recovery and Education)  
1.800.366.6777  
www.core.org

### Sandrine's Gift

www.organtransplants.org





**Palliative Care** no longer means helping children die well, it means helping children and their families to live well and then, when the time is certain, to help them die gently.

— Mattie Stepanek (1990-2007)



384 Fox Chapel Road, Pittsburgh, PA 15238 ■ 412.963.8243

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