The Pediatric Palliative Care Coalition (PPCC) is pleased to provide this Care Plan Book and hopes that it will make your job as a caregiver a little bit easier. We understand how overwhelming and difficult that task can be. Our goal is that this reference guide, to be used by families, caregivers and medical professionals, will become an invaluable source for you and everyone involved in your journey.

We would like to acknowledge and thank the National Center for Medical Home Implementation for their extensive list of helpful forms. In order to create this Care Plan Book, a team of medical professionals, parents and volunteers reviewed and adapted the forms they felt would be most helpful to our families. All of the original forms, and many more, are available on their website:www.medicalhomeinfo.org/for_families/care_notebook/

We would also like to thank the numerous volunteers who have worked tirelessly to make this comprehensive book a reality, including many different voices, both medical professionals and family members. Thanks, as well, for the beautiful design work by Kristi Schaefer and Scot Wallace at SWZ Design.

The Pediatric Palliative Care Coalition is a statewide organization that provides resources for families, volunteers and medical professionals caring for children with life-limiting illnesses. Our goal is to provide a clearer path for children and their families coping with this difficult, life-altering experience. We strive to provide comprehensive, up-to-date information on pediatric palliative and hospice care across Pennsylvania through education, advocacy, information/resources and volunteerism.

We count on the support and participation of all those across the state who are involved in pediatric palliative and hospice care. We would love to have you join us!

To find out more information about PPCC and to learn about our activities or to make a donation, please visit our website at www.ppcc-pa.org.

Betsy Hawley

Executive Director

Key Contacts



Family

Parent/Guardian	
	Work Phone
Cell Phone	Email
Parent/Guardian	
Address	
	Work Phone
Cell Phone	Email
Relative/Relationship	
Phone #	
Relative/Relationship	
Phone #	
Relative/Relationship	
Phone #	
Medical	
	Poison Control #
	Police #
FIIONE #	
School	
CONTOC	
School	
Phone #	

Doctor/Specialt	У		
Doctor/Specialty	y		
	y		
	y		
	y		
Doctor/Specialty	y		
Doctor/Specialty	y		
Phone #			
	y		
Phone #			
	y		
Phone #			
	y		
Phone #			
	y		
Special Transpo	rtation		
Medical Appts/Pho	one#		
School/Phone#			
Utilities (conta	act each for a Medical Neces	ssity Form)	
	Phone #	- · · · · · · · · · · · · · · · · · · ·	
	Phone #		
	Phone #		
	Phone #		
Other			

Doctors/Therapists



Doctors

Primary Care	 	
Location	 	
	Email	
Emergency	 	
Specialist	 	
Location	 	
Address	 	
	Email	
Emergency	 	
Specialist	 	
	Email	
Emergency		
Specialist	 	
	Email	
Emergency	 	
Specialist		
	Email	

Specialist			
Address			
		Email	
Emergency			
Professional Re	sources		
Name			
Location			
Address			
Phone	Fax	Email	
Emergency			
Name			
		Email	
Name			
		Email	
Name			
Phone	Fax	Email	
Emergency			
Name			
Address			
		Email	
Emergency			

Pharmacies/Hospitals



Pharmacies			
Main			
			Email
Business Hours _		Contact	
Other			
Phone	Fax		Email
Business Hours _		_ Contact	
Other			
Phone	Fax		Email
Business Hours _		_ Contact	
Other			
Address			
			Email
Business Hours _		_ Contact	
Other			
			Email
Business Hours _		Contact	
Other			
			Email
Business Hours _		_ Contact	

Hospitals			
Main			
Medical Record #			
		Email	
Other			
Medical Record #			
Emergency Departm	ent #		
		Email	

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Child's Name

Notes

Transportation



			Special Transp	ortation (to and from so	:hool)	
Ambulance			Contact			
Company			Agency			
	Fax			Fax	Email	
			Important Informa	ation (bus route, rules reg	garding pick-up, etc.)	
Special Transp	oortation (to and from m	edical/therapy appointments)				
Contact						
Agency						
	Fax					
Important Informa	ation (bus route, rules reg		Notes			
Special Transp	ortation (to and from me	edical/therapy appointments)				
	•	ечісаў пегару арроіншеніз)				

Agency Address _____ Phone _____ Fax _____ Email _____

Important Information (bus route, rules regarding pick-up, etc.)

School/Daycare



School Name _			Name			
Address			Title			
		Email			Email	
Nurse			Name			
				Fax		
Teacher				rax		
Teacher					Email	
Principal						
				Fax		
Guidance Cour	nselor		Name			
				Fax_		
Special Educat	tion Director					
Transportation	Contact				Email	
			Name			
Homebound Co	oordinator					
Phone #				Fax		
			Name			

Additional Contacts (PT, OT, Nutritionist, Therapist, etc.)

Email



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Child's Name

Date of Birth





				Fuse box or breaker box	is located
Parent/Guardian				_ Fire extinguisher is locate	ed
Will be at phone				_ Flashlights are located	
Will be home at					
				For EMT or ER persor	nnel
Special instructions				Allergies	
				Baseline data	
Significant events in the past 48 h	ours				Site best taken
				BP	Site best taken
				Temp	Site best taken
				Resp rate/minute	Oxygen saturation
				Skin color	Best blood draw site
Medications				Pupils	
Name	Strength	Dosage	Time to be given		
				Communication	
				Preferred method	Language
				_ How child expresses pair	n
				_	
					et or overstimulate my child
				(loud noises, bright lights, medica —	al equipment, separation from parents/special item, touch, etc.)
	. L			_	
Call 911 in case of emergency	-	5		These things can help	p calm my child
Child's Name				_	
Home Phone				_	
Address					
Driver Octob Dec. 1 (D)				Insurance	
Primary Care Doctor/Phone				Company	Policy #
Other person to call in case of eme	ergency			Policyholder Name	Group #

In home

Extra equipment/supplies are located

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Child's Name

Date of Birth



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				Fuse box or breaker box	is located		
Parent/Guardian				Fire extinguisher is located			
Will be atp	hone	cell		_ Flashlights are located _			
Will be home at				_			
				For EMT or ER person	nnel		
Special instructions				Allergies			
				Baseline data			
Significant events in the p	ast 48 hours			Pulse rate	Site best taken		
					Site best taken		
				Temp	Site best taken		
				Resp rate/minute	Oxygen saturation		
				Skin color	Best blood draw site		
Medications				Pupils			
Name	Strength	Dosage	Time to be given				
				Communication			
				Preferred method	Language		
				_ How child expresses pai	in		
					set or overstimulate my child al equipment, separation from parents/special item, touch, etc.)		
Call 911 in case of em Child's Name Home Phone	Date o			These things can hel	p calm my child		
Address							
Primary Care Doctor/Pho	ne			Insurance	Dell'ess "		
Other person to call in cas					Policy #		
p				 Policyholder Name 	Group #		

Child's Name

Date Last Revised:

In home

Extra equipment/supplies are located



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				Fuse box or breaker box	is located		
Parent/Guardian			·	Fire extinguisher is located			
Will be at	phone	cell		_ Flashlights are located _			
Will be home at				_			
				For EMT or ER person	nnel		
Special instructions				Allergies			
				Baseline data			
Significant events in the	oast 48 hours			Pulse rate	Site best taken		
					Site best taken		
				Temp	Site best taken		
				Resp rate/minute	Oxygen saturation		
				Skin color	Best blood draw site		
Medications				Pupils			
Name	Strength	Dosage	Time to be given				
				Communication			
				Preferred method	Language		
				How child expresses pai	n		
				-	set or overstimulate my child al equipment, separation from parents/special item, touch, etc.)		
	nergency Date o			These things can help	p calm my child		
Address				_			
Address							
Primary Care Doctor/Phy	one			Insurance			
<u>-</u>	se of emergency				Policy #		
other person to call in ca	or entergency			Policyholder Name	Group #		

Child's Name

Date Last Revised:

In home

Extra equipment/supplies are located

Child's Insurance



Primary

Parent/Guardian				
Child's Name				
Insurance Company				
Address	City	State	Zip	
Contact/Phone #				
Name of Insured	Policy #	Group #		
Policy Effective Dates				
Employer Name				_
Address			Zip	

Secondary

Parent/Guardian		
		Birth
Insurance Company		
		State Zip
Contact/Phone #		
Name of Insured	Policy #	Group #
Policy Effective Dates		
Employer Name		
Address	City	State Zip

Coverage

What is covered and co-pay	y for the following:	
Procedure	Covered	Co-Pay
Doctor's Office Visits		
ER Care		
Surgeries		
Outpatient Hospital Care		
Doctor's Hospital Visits		
Hospitalizations		
Durable Medical Equipment		
Orthotic/Prosthetic Devices		
Medical Supplies		
Prescribed Medications		
Home Care		
Skilled Nursing Care		
Medical Treatment		
Therapy (kind)		
Other		
Diagnostic Tests		
Laboratory		
X-rays		
Other		
Ambulance		
Dental Care		
Mental Health Care		
Inpatient		
Outpatient	•	

What is not covered by insurance:

pediatric palliative care coalition°	Child's Name	Date of Birth
	Date Last Paviands	



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Child's Name

Date of Birth

Medical Bill Tracking Form



	Date	Provider	Service	Cost	Insurance Company Paid/Date	Family Paid/Date
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Child's Name

Date of Birth

Income Tax Expense Record



	Date	Expenses	Medical	Travel (To/From/Mileage/Other)	Cost
	 				
	 				
	 				
	•				
-					

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Child's Name

Date of Birth

Medical Supplies/Equipment



Item Description/Product Code	Item Description/Product Code
Provider/Vendor Name	Provider/Vendor Name
Contact Person	Contact Person
Phone Faxemail	Phone Faxemail
Prescribed by	Prescribed by
Reason Prescribed	Reason Prescribed
Contact for Service/Insurance Approval	Contact for Service/Insurance Approval
Phone	Phone
Comments (kind of services needed, part numbers, costs, etc.)	Comments (kind of services needed, part numbers, costs, etc.)
Item Description/Product Code	Item Description/Product Code
Provider/Vendor Name	Provider/Vendor Name
Contact Person	
Phone Faxemail	Phone Faxemail
Prescribed by	
Trescribed by	
Reason Prescribed	Prescribed by
	Prescribed byReason Prescribed
Reason Prescribed	Prescribed by

Family Health History



Family Health History

Date of Birth

Biological Family History

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Mother's and Father's Health His	tory			Is there anyone in the family with a	similar di	sability or	chronic illness as your child?
Diabetes	■ Mother	☐ Father		□ Yes □ No			
High Blood Pressure	■ Mother	☐ Father		If yes, who/what:			
Smoker	■ Mother	☐ Father					
Kidney Problems	■ Mother	☐ Father					
Asthma	■ Mother	☐ Father		Is there anyone in the family with:			Relationship to child
Epilepsy, Seizures	■ Mother	☐ Father		Genetic conditions	☐ Yes	☐ No	
Birth Defects*	■ Mother	☐ Father		Heart problems	☐ Yes	☐ No	
Deafness	■ Mother	☐ Father		Developmental disabilities	☐ Yes	☐ No	
Death under 50 years of age	■ Mother	☐ Father		Seizure disorder	☐ Yes	☐ No	
Other*	■ Mother	☐ Father		Cerebral Palsy	☐ Yes	☐ No	
DES Use	■ Mother	☐ Father		Diabetes	☐ Yes	☐ No	
Menstrual Problems*	■ Mother	☐ Father		Blood disorder	☐ Yes	☐ No	
Heart Attack under 60 years of age	■ Mother	☐ Father		Cancer	☐ Yes	□ No	
Stroke	■ Mother	☐ Father		Vision and/or hearing impairment	☐ Yes	□ No	
Stomach/Intestinal	■ Mother	☐ Father		Metabolic or nutritional disorder	☐ Yes	□ No	
Intellectual Disability	■ Mother	□ Father		Cleft Palate	☐ Yes	☐ No	
Blood Disease	□ Anemia	☐ Sickle Cell	☐ Other*	Other	☐ Yes	□ No	
Allergies	■ Mother	□ Father					
Bone/Joint Problems	■ Mother	☐ Father		Has anyone in the family had genet	ic testing	or couns	eling?
High Cholesterol	■ Mother	☐ Father		☐ Yes ☐ No ☐ Don't know If ye	es, please	describe	:
Cancer (Type)	■ Mother	☐ Father					
Urinary Problems	■ Mother	☐ Father					
Muscle/Nerve Disease	■ Mother	☐ Father		Are there any other family health in	formation	that migh	nt be related to your child's
				special health needs?			
*Please explain:							

Child's Name

Birth History

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Child's Name				How many months were you pregnant when you first saw a doctor?
	/ Birthweight	Length	_	
Birth Order (1st, 2nd	d, etc.)			How many times did you visit the doctor during your pregnancy?
Obstetrician				Drugs/medications taken during pregnancy:
	City			
	Cell			
				Any illnesses or problems during the pregnancy?
Hospital where c	hild was born			☐ Yes ☐ No If yes, please describe:
Address	City	State	Zip	
Phone				
				Was the baby full-term (37 weeks or more)?
Name of child's p	orimary doctor			☐ Yes ☐ No If no, number of weeks of gestation?
Address	City	State	Zip	Length of labor
Phone				
Notes				Delivery method: ☐ Normal ☐ Caesarean ☐ Breech ☐ Precipitate (sudden)
Notes				Child's Apgar scores at 1 minute; at 5 minutes
				Child's condition at birth
				Child was fed: ☐ breast milk ☐ formula (brand)
				Child's age at hospital discharge
				Child was in the hospital from/ to/ to/

Child's Name

Date Last Revised:

Eating History

When your child came home from the hospital, what type of food did he/she eat: ☐ breast milk ☐ regular formula ☐ special formula ☐ other	How long does it take your child to finish a bottle or eat a meal?
Changes in feeding Breast to bottle child's age why change?	Are there any problems (vomiting, choking, swallowing, refusing to eat, diarrhea, etc.)?
Formula change child's agewhy change and changed to what?	
Bottle to cup child's age why change?	Notes
Started solid food child's age	
Food allergies	
Textures	
NPO & Tube Feedings	
Other changes	

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Child's Name

Date of Birth



Developmental Milestones

This list can be used as a guide and for any questions you may have for your child's physician.

	Age	Notes/Questions
Smiled		
Laughed out loud		
Held up head		
Rolled over		
Sat up		
Sat alone		
Got first tooth		
Started solid food		
Drank from glass/cup		
Used utensils		
Crawled		
Spoke first word		
Waved "bye"		
Walked		
Walked alone		
Spoke first sentence		
Toilet		
Indicated need		
Toilet trained - bladder		
Toilet trained – bowel		
Dressed self		
Washed self		
Other		
Othor		

Notes

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Child's Name

Date	Last	Revi	sed	:
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Dental History



Notes

Dentist						
Address		City		State	Zip	
Phone			Email _			
Dental Specialist						
Address		City		State	Zip	
Phone	Cell		Email			

All children should have routine dental care; such care may be even more important when your child has a special health care need. Consult with your family dentist or your child's medical specialist to determine if specialized dental services are required.

Before the dental exam, the dentist should have information about your child's medical condition and current care. Discuss any precautions recommended by your child's medical specialist as well as provide a list of current medications your child is taking.

Dentist has been informed of medical condition, medications, allergies (latex or other) and medical specialist's recommendations.

Date	Appointment Time	What Occurred at Appointment	Follow-up Information (Sedation provided/Antibiotics Given/Needed)

oediatric	palliative	care	coal	lition

Child's Name

Date	Last	Roy	ricor	1-

Test Results



W . T 1	_

□ Blood □ X-ray □ CT □ MRI □ Other	Date Performed	💶 🗀 Blood 🗅 X-ray 🗅 CT 🗅 MRI 🗅 Other	Date Performed
Doctor who ordered test		Doctor who ordered test	
Phone		Phone	
Description			
Results			
Location of Test Record			
Phone		Phone	
Comments		Comments	
□ Blood □ X-ray □ CT □ MRI □ Other	Date Performed	□ Blood □ X-ray □ CT □ MRI □ Other	Date Performed
Doctor who ordered test			
Phone			
Description			
Results			
Location of Test Record			
Phone		Phone	
Comments		Comments	

Test Results



W . T 1	_

□ Blood □ X-ray □ CT □ MRI □ Other	Date Performed	💶 🗀 Blood 🗅 X-ray 🗅 CT 🗅 MRI 🗅 Other	Date Performed
Doctor who ordered test		Doctor who ordered test	
Phone		Phone	
Description			
Results			
Location of Test Record			
Phone		Phone	
Comments		Comments	
□ Blood □ X-ray □ CT □ MRI □ Other	Date Performed	□ Blood □ X-ray □ CT □ MRI □ Other	Date Performed
Doctor who ordered test			
Phone			
Description			
Results			
Location of Test Record			
Phone		Phone	
Comments		Comments	

Test Results



W . T 1	_

□ Blood □ X-ray □ CT □ MRI □ Other	Date Performed	💶 🗀 Blood 🗅 X-ray 🗅 CT 🗅 MRI 🗅 Other	Date Performed
Doctor who ordered test		Doctor who ordered test	
Phone		Phone	
Description			
Results			
Location of Test Record			
Phone		Phone	
Comments		Comments	
□ Blood □ X-ray □ CT □ MRI □ Other	Date Performed	□ Blood □ X-ray □ CT □ MRI □ Other	Date Performed
Doctor who ordered test			
Phone			
Description			
Results			
Location of Test Record			
Phone		Phone	
Comments		Comments	

Illness/Infection/Injury History



Illness/Infection/Injury	Date	Duration	Drugs Taken	Physician	Location	Treatment
	-					
	-					
	-					
	1		<u> </u>	<u> </u>		

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Child's Name

Date of Birth



Diagnosis	Abbreviation	Also Called	Physician Who Diagnosed	Physician's Specialty	Date of Diagnosis

pediatric palliative care coalition°	Child's Name	Date of Birth
	Date Last Revised:	

Immunization and Allergy Record



	Date	Physician	Reaction	Date	Physician	Reaction
Hepatitis B						
Diptheria/Tetanus (DT)						
Diptheria/Pertussis/Tetanus (DPT)						
Tetanus						
Polio						
Influenza Type B						
Measles/Mumps/Rubella (MMR)						
Measles (Rubeola)						
Mumps						
Rubella (3-day Measles)						
Varicella Zoster						
Meningococcal Conjugate Vaccine						
Other:						
TB Skin Tests (PPD)						
Lead Screening						
Other:						

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Child's Name

Date of Birth

Appointments/Meetings Log



Use this form to keep track of meetings and appointment you have about your child's health care.

Call/Meeting	Date/Time	Name of Person/Agency	Contact Information	What was Discussed/Decided

pediatric palliative care coalition°	Child's Name	Date of Birth
	Date Last Revised:	

Appointments

Date/Time	Hospital	Doctor/Specialty	Questions/Results/Comments/Follow-up

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Hospital Stays



Date of Admission/ Date of Discharge/	Date of Admission/ Date of Discharge/
Reason for Admission	Reason for Admission
Hospital	Hospital
Address City State Zip	Address City State Zip
Phone	Phone
Doctor/Surgeon	Doctor/Surgeon
Type of Surgery/Procedure	Type of Surgery/Procedure
Outcome	Outcome
Date of Admission/ Date of Discharge/	Date of Admission// Date of Discharge//
Reason for Admission	Reason for Admission
Hospital	Hospital
Address City State Zip	Address City State Zip
Phone	Phone
Doctor/Surgeon	Doctor/Surgeon
Type of Surgery/Procedure	Type of Surgery/Procedure
Outcome	Outcome

Hospital Stays



Date of Admission/ Date of Discharge/	Date of Admission/ Date of Discharge/
Reason for Admission	Reason for Admission
Hospital	Hospital
Address City State Zip	Address City State Zip
Phone	Phone
Doctor/Surgeon	Doctor/Surgeon
Type of Surgery/Procedure	Type of Surgery/Procedure
Outcome	Outcome
Date of Admission/ Date of Discharge/	Date of Admission// Date of Discharge//
Reason for Admission	Reason for Admission
Hospital	Hospital
Address City State Zip	Address City State Zip
Phone	Phone
Doctor/Surgeon	Doctor/Surgeon
Type of Surgery/Procedure	Type of Surgery/Procedure
Outcome	Outcome

Hospital Stays



Date of Admission/ Date of Discharge/	Date of Admission/ Date of Discharge/
Reason for Admission	Reason for Admission
Hospital	Hospital
Address City State Zip	Address City State Zip
Phone	Phone
Doctor/Surgeon	Doctor/Surgeon
Type of Surgery/Procedure	Type of Surgery/Procedure
Outcome	Outcome
Date of Admission/ Date of Discharge/	Date of Admission// Date of Discharge//
Reason for Admission	Reason for Admission
Hospital	Hospital
Address City State Zip	Address City State Zip
Phone	Phone
Doctor/Surgeon	Doctor/Surgeon
Type of Surgery/Procedure	Type of Surgery/Procedure
Outcome	Outcome



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Child's Name

Date of Birth



Date	Hospital/Medical Facility	Doctor	Admitted?	Results/Comments
	I	<u> </u>	L	1

pediatric palliative care coalition°	Child's Name	Date of Birth
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Tips for a Good Visit



This information can be helpful for the doctor and others to know.

Notes

Child's Nickname

My child is verbal ☐ Yes ☐ No

My child likes it when you:

My child does not like it when you:

If my child does not want to do something, here are things that can help:

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Child's Name

Things to Remember for Next Visit



Date			
pediatric palliative care o	eoalition ^o	Child's Name	Date of Birth

Daily Treatments/Regimen



Bowel/Bladder Regimen (If you have a Plan of Care, please insert copy here.) Vital Signs (Frequency) **Respiratory Treatments** (O₂, trach, vent, etc.) Adaptive Equipment (wheelchair, braces, splints, communication devices, etc.) Trach **Feeding Tube**

Seizure Activity



Date/Time	Description	Duration	Treatment Given (Breathing/Meds)
	·		•

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Child's Name

Date of Birth

Catheterization Information

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Date	Time	Amount of Urine	Comments	Date	Time	Amount of Urine	Comments
				_			
				_			
				_			
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				_			

Child's Name

Date Last Revised:

Catheterization Information

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Date	Time	Amount of Urine	Comments	Date	Time	Amount of Urine	Comments
				_			
				_			
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Child's Name

Date Last Revised:

Catheterization Information

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Date	Time	Amount of Urine	Comments	Date	Time	Amount of Urine	Comments
				_			
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Child's Name

Date Last Revised:

Albuterol, Nebulizer, and Vest® Treatments



Date	Time	Neb Given	O ₂ sat Pre	O ₂ Sat Post	Vest® Given	O ₂ sat Pre	O ₂ Sat Post	Comments	Initials

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Child's Name

Date of Birth

Blood Glucose Record



Date	Time	Blood Glucose	Insulin (Type and Dose)	Site	Symptoms	Actions Taken

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Child's Name

Date of Birth

Blood Glucose Record



Date	Time	Blood Glucose	Insulin (Type and Dose)	Site	Symptoms	Actions Taken

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Child's Name

Date of Birth

Blood Glucose Record



Date	Time	Blood Glucose	Insulin (Type and Dose)	Site	Symptoms	Actions Taken

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Child's Name

Date of Birth

Treatment/Therapy Routines



(Describe any special routines and time - suctioning, skin care, therapies, postural drainage, etc.)

Routine	Description	Time Performed

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Child's Name

Date of Birth



☐ Physical	☐ Occupational	☐ Developmental	☐ Nutrition	□ Spe	ech 🛭 Vision	☐ Hearing			
Activity					Comments				
						·		 	
								 	
pediatric	palliative care	coalition°				Child's Nar	me	Date of Birth	
						Date Last Revise	ed:		



☐ Physical	☐ Occupational	☐ Developmental	☐ Nutrition	□ Spe	ech 🛭 Vision	☐ Hearing			
Activity					Comments				
						·		 	
								 	
pediatric	palliative care	coalition°				Child's Nar	me	Date of Birth	
						Date Last Revise	ed:		



☐ Physical	☐ Occupational	☐ Developmental	☐ Nutrition	□ Spe	ech 🛭 Vision	☐ Hearing			
Activity					Comments				
						·		 	
								 	
pediatric	palliative care	coalition°				Child's Nar	me	Date of Birth	
						Date Last Revise	ed:		

Baseline Data



Normal Vital Signs

Pulse rate	Site best taken					
BP	Site best taken					
Temp	Site best taken					
Resp rate/minute						
	Oxygen saturation					
Skin color						
Best blood draw site						
Pupils (normal, dilated, constricted, equal)						

Systems	ОК	Problem	Comments/Description
CNS/Sensory		۵	
Heart/Blood (include recent blood counts)			
Gastrointestinal			
Respiratory (describe breath sounds)			
Gentourinary			
Muscoskeletal			
Baseline Xray findings			
Developmental			
Other:			

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Normal Status

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Areas to Check	Normal Status is	N/A
Rash		
Drainage		
Nose		
Eyes		
Ears		
Fontanels		
Seizure activity		
Verbal skills		
Activity level		
Vent dependent/trach/C-pap		
Motor skills		
Upper body extremities		
Lower body extremities		
Stool		
Urine		
Feeding behaviors/Source		
Ostomy sites		
Behavior/attitude		
Sleeping patterns		
Blood sugars		
Communication		
Other:		

Child's Name

Date Last Revised:



Food/Drug/Other	Reaction	What To Do (Give EpiPen®, Meds, Call 911, etc.)	Date Noted

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	Date Last Revised:	

All About Me



My Name My Nickname	I like to do these things in my free time				
I live at ☐ Home ☐ School ☐ Foster Home ☐ Hospital ☐ Other					
Family member names (first name/last name/relationship)	I usually go to bed at				
	Before bed, I usually				
	Things I need help with (i.e. brushing teeth, v	washing, dressing, etc.)			
Close friends, babysitters, neighbors (first name/last name/relationship)					
	Things I can do myself				
Pets (Type/Name)					
	Other				
Favorite Foods					
Least Favorite Foods					
Favorite Songs/Music					
Favorite Toys/Games					
Favorite Hobbies/Other Things					
Favorite TV Shows/Computer Games					
Favorite Friends					
Favorite People					
nediatric palliative care coalition ^o	Child's Name	Date of Birth			

Preferences



	Notes
Communication	
Can she/he be understood by others?	
Preferred language/methods of communication:	
☐ Talk ☐ Sign ☐ TTY ☐ Picture board ☐ Computer keyboard ☐ Gesture/facial	
☐ Other	
Are there specific words/gestures that have special meaning?	
Name of interpreter if required:	
Is your child deaf/hearing impaired?	
Is your child legally blind/visually impaired?	
Child's Ethnicity	
Family's preferred language:	
Family's religious beliefs/customs that may affect treatment:	

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Child's Name

Personal Care and Hygiene



Other helpful information (i.e. shoe and clothing size, menstrual cycle, etc.)

Independent

Things that I can do independently (i.e. brushing teeth)

Assistance

Things that I need assistance with

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Child's Name

Date of Birth

Home Health Agency



Agency Name				Notes
Phone	Fax	Email		
Service(s) to be	provided (i.e. nursing, therap	oy, home health a	aide, etc.)	
Service	Frequency (visits/week)	Hours/Visit	Last Authorization Date	
			 	

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Child's Name

Date of Birth

Home Schedule



Time	Name (Home Health Care/Aide)	Туре	Phone#	Comments
	<u> </u>			
	Time	Time Name (Home Health Care/Aide)	Time Name (Home Health Care/Aide) Type Type	Time Name (Home Health Care/Aide) Type Phone#

pediatric palliative care coalition°	Child's Name	Date of Birth
	Date Last Revised:	

Caregiver Task Sheet



Task	М	т	w	Th	F	Sa	Su

pediatric palliative care coalition°	Child's Name	Date of Birth
	Date Last Revised:	

Respite Care Log



Respite Care Pro	ovider		Respite Care Pr	ovider		
Date of Service			Date of Service			
Agency Name						
Contact Person _			Contact Person _			
Address			Address			
Phone	Fax	Email		Fax		
Respite Care Pro	ovider		Respite Care Pr	ovider		
Date of Service			Date of Service			
Agency Name						
Contact Person _			Contact Person _			
Address						
Phone	Fax	Email			Email	
Respite Care Pro	ovider		Respite Care Pr	ovider		
Date of Service			Date of Service			
Contact Person			Contact Person _			
Phone	Fax	Email		Fax		
Respite Care Pro	ovider		Respite Care Pr	ovider		
-			-			
= -						
	Fax			Fax		

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Transportation



Checklist for Traveling

Seating Instructions (i.e. car seat, wheelchair, best place to sit, etc.)

Instructions for field trips at program/school

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Child's Name

Transportation Bags



	M	т	W	Th	F	Sa	Su
School Backpack							
<u> </u>							
Other School Bags							
Portable Bag							
Markari Dan							
Medical Bag							
Any Car Trip Items							

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Child's Name

Date of Birth





Allergies

Pharmacy			
Address			
Phone	Fax	Email	

Medication Name	Start Date	End Date	Dosage	Dosage Route	Time of Day Given	Reason for Med	Prescribed by	Side Effects	Observed

Always ask your Health Care Provider or Pharmacist about your medications.

pediatric palliative care coalition°	Child's Name	Date of Birth
	Date Last Revised:	



Allergies

Pharmacy			
Address			
Phone	Fax	Email	

Medication Name	Start Date	End Date	Dosage	Dosage Route	Time of Day Given	Reason for Med	Prescribed by	Side Effects	Observed

Always ask your Health Care Provider or Pharmacist about your medications.

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	Date Last Revised:	

Medication Schedule

Physician _____ Address _____



Reason for Medications

Allergies/Other important information

	Phone		Email			
	Order Date	Medication	Concentration Form	Dosage/Direction	Schedule	Route
•						

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Child's Name

Date of Birth

Feeding History



When your child came home from the hospital, what type of food did he/she eat:	Notes
□ breast milk □ regular formula □ special formula □ other	_
Changes in feeding	
Breast to bottle child's age why change?	
Formula change child's age why change and changed to what?	
why change and changed to what?	-
-	
Bottle to cup child's age why change?	_
Started solid food child's age	
Other changes	
How long does it take your child to finish a bottle or eat a meal?	
Are there any problems (i.e. vomiting, choking, refusing to eat, diarrhea, etc.)?	
, , , , , , , , , , , , , , , , , , ,	

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Gastrostomy Tube Feeding



Formula	Strength
---------	----------

Date	Start Time	Stop Time	HOB Elevated	Check Tube Site	Check Placement	Check Patency	Water Flush/Amount (cc	Tolerated Well	Comments	Initials
		_								
		-								
		-								
		-								
		-			 					
		-								
		1								
					1					

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Child's Name

Date of Birth

Mealtime Routine



	Day/Date	Fed Via (Mouth, Tube, etc.)	Food Amount	Water Amount	Equipment/Utensils/Positioning		
Breakfast							
Lunch							
Dinner							
Snacks							
Breakfast							
Lunch							
Dinner							
Snacks							
Breakfast							
Lunch							
Dinner							
Snacks							
Breakfast							
Lunch							
Dinner							
Snacks							
Current Diet				Favorite Food	ds		
Food Allergies/R	Reaction			Least Favorite Foods			
Foods to Avoid				Feeding Tips			
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School/Daycare



School/Daycar	e Name		Name		
Phone	Fax	Email	Phone	Fax	
Nurse			Name		
Phone #			Title		
				Fax	
Teacher					
Teacher				Fax	
Phone #					
Principal					
Phone #					Email
Guidance Cou	nselor		Name		
Phone #					
				Fax	
Special Educat	tion Director				
Phone #			Name		
			Title		
Transportation	Contact		Phone	Fax	Email
Phone #					
			Name		
Homebound Co	oordinator				
				Fax	
			Name		

Phone _____

Additional Contacts (PT, OT, Nutritionist, Therapist, etc.)

Email

School/Daycare Schedule



School/Day	care Center		
Address			
Phone	Fax	Email	

Day	Arrives	Leaves	Has Therapy (Y/N)	Type(s) of Therapy	Specialty Class(es)	Supplies Needed	Breakfast Begins	Lunch Begins	Nap Begins	Snack Begins
M										
<u> </u>										
w										
тн										
F										
							<u> </u>	<u> </u>		<u> </u>

ре	ediatric palliative c	are coalition [®]	Child's Name	

After School Center Schedule



After School Center			
Address			
Phone	Fax	Email	

Day	Arrives	Leaves	Has Therapy (Y/N)	Type(s) of Therapy	Specialty Class(es)	Supplies Needed	Lunch Begins	Nap Begins	Snack Begins
M									
<u> </u>									
w									
ТН									
F									

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Child's Name

IFSP/IEP/ISP Notes



Meeting Date Meeting Purpose	Name/Phone	
Issues/Concerns/Questions	Responses/Solutions/Answers	
Outcome of meeting	Things to do/remember	
Next steps		
	Next meeting date	
pediatric palliative care coalition°	Child's Name	Date of Birth
	Date Last Revised:	

Moving Checklist

As soon as you know when and where you are moving	Have copies of		
☐ Contact your child's health insurance plan	☐ Medical records☐ School records		
☐ Ask all current health care providers to make referrals for new providers			
☐ Contact phone company for phone book	☐ IEPs, IFSPs, IHCPs, and other care plans		
☐ Contact local emergency medical service (EMS)	☐ Shot and immunization records		
☐ Contact local school system	☐ List of medical supplies used		
☐ Contact State Department of Education for information on Special Education	☐ Prescriptions		
☐ Contact Chamber of Commerce for information about new community	☐ Health insurance card		
☐ Visit the area, take pictures, and video tape, if possible	☐ Letter from PCP and specialty providers expelling child's condition		
☐ Contact current medical equipment supplier			
☐ Learn about religious and special interest organizations	New phone numbers		
☐ Locate pharmacy that accepts your health insurance	HospitalHealth care providersHealth insurance plan		
☐ Contact parent organizations and support groups			
☐ Call another parent in the area			
Two weeks before moving			
☐ Get new written prescriptions from your child's health care providers			
☐ Contact new school again			
☐ Send school reports	Electric Company		
☐ Send (or have sent) medical records to new health care providers	Phone Company Gas/Oil Company School		
☐ Notify electric company of moving date			
☐ Call phone company and set up new phone number	Parent Support Group/Organizations		
☐ Call medical equipment supplier	State Department of Education		
Two days before moving	State Department of Health		
☐ Refill prescriptions	Equipment Supplier		
☐ Make sure electricity has been turned on in new home	Pharmacy House of Worship Other		
☐ Make sure phone is connected in new home			
☐ Check supplies for trip			
☐ Call new medical equipment supplier			
podiatria palliativa cara coalition:	Child's Name		



In this section, you will find sample letters you can use as a guide when you write to your community service providers. Change them for your own situation. Be sure to include your address, daytime phone number, and the date on all letters you write, and be sure to keep a copy of every letter you send. If your family's situation and/or needs change, send updates to these providers.

- ☐ To EMS, Police, and/or Fire Department written by parent/guardian
- ☐ To EMS written by Primary Care Provider
- ☐ To Electric Company written by Primary Care Provider
- ☐ To Gas Company written by Primary Care Provider
- ☐ Requesting Supplies for Incontinence written by Primary Care Provider
- ☐ Medical Necessity written by Primary Care Provide
- ☐ Medical Necessity for Formula and Nutritional Supplement written by Primary Care Provider

pediatric palliative care coalition

Child's Name

To EMS, Police, and/or Fire Department written by parent/guardian

From: Your Address, City, State, Zip To: Company Address City, State, Zip To Whom It May Concern, This letter will introduce you to my fourteen-year-old son Daniel - "Danny" to his friends. My son is a wonderful young man who likes cats, Nintendo, and practical jokes. Danny has cerebral palsy, a seizure disorder, asthma, and a "Mickey" gastrostomy button. It is important for you to know some of these details in order for you to provide the best care possible in case of an emergency. Danny's bedroom is located on the first floor of our home (the second door on the left when you come through the front door). He uses a manual wheelchair for mobility and needs assistance with transfers. He is nonverbal and uses a 'Touch Talker' computer to communicate. He is able to direct you to any pain or discomfort he is having. Danny has grand mal seizures which usually leave him with temporary weakness on his left side. If his seizure is strong, he sometimes loses consciousness. He also tends to have seizures when he spikes a temperature. His asthma is usually controlled with medication and the use of his nebulizer, which makes electricity a priority in our home. Danny's nutritional needs are met through his 'G' button. He uses an electric kangaroo pump. I have enclosed a picture of Danny so you can put a face with this introduction. I am also sending a copy of his Emergency Information Form for Children with Special Needs. I encourage you to share this letter with fire fighters and EMTs in your station. I will also be sending this letter to the Police Department and local electric company. We hope that Danny won't need your services any time in the near future. But if he does, you now have a clearer picture of his basic needs. I will call you next week to see if you have any questions. Thank you for your time and attention. Sincerely, (parent/guardian full name) Danny's Primary Care Provider

Danny's Health Insurance Plan ____

Hospital of choice

To EMS, Police, and/or Fire Department written by Primary Care Provider (written on Primary Care Provider's stationery)

Date:

Company Address City, State, Zip

Re: Name of Child DOB: Child's birth date

Parent/guardian: Parent/guardian full name

Phone: Your home phone number

To Whom It May Concern,

(Name of Child) is a (child's age) old child with (diagnoses) requiring continuous (type of care needed). Currently, (Name of Child) received (number of hours/week of skilled nursing in home with the parents assuming the responsibility for the remainder of his/her care.

(Name of Child) is at risk for recurrent respiratory distress and may require emergency medical treatment and/or resuscitation. The home is equipped with (type of equipment used). The parents have been trained in CPR. If the parents or the nurse on duty needs to resuscitate (Name of Child) and have difficulty, they will call for help. Therefore, if your department receives a call from this household, immediate response is critical. In the event of an emergency, (Name of Child) should be transported to (hospital of your choice) Emergency Room via local ambulance.

Most of (name of child)'s medical equipment requires electrical service and his medical condition requires daily medical treatment in the home. Therefore, it is critical that the electric company maintains electricity to this home.

Please place the name of this family on a 'Top Priority' list for restoration of electricity in the event of a power failure. It is urgent that the family is notified of arrangements for an emergency generator for power.

Please place the name of this family on a 'Top Priority' list for restoration of telephone services in the event of a telephone failure. It is very important to the future of this child that the family be protected by this 'First Respond' alert.

Sincerely,

(name of Primary Care Provider)

cc: Name and contact information for parent/guardian Town/City/Police and Fire Departments Electric/Gas/Oil/Telephone Companies Department of Public Works



To Electric Company written by Primary Care Provider (written on Primary Care Provider's stationery)

Date:

Company Address City, State, Zip

Re: Name of your child DOB: Child's birth date

Parents/guardian: Parent/guardian full name

Phone: Your home phone number

To Whom It May Concern,

I am the primary care provider for (Name of Child), who lives at (address, city, zip). (Name of Child) is a child with special health needs who requires the use of (type of equipment used).

This equipment requires electricity to run. Failure to operate this equipment seriously jeopardizes my patient's health. Therefore, it is essential that this family's electricity remain turned on at all times.

Please call me or (name of individual) at (phone number) if you have any questions.

Thank you.

Sincerely,

(name of Primary Care Provider contact/company)

cc: (name of parent/guardian)



To Gas/Electric/Heating Oil, Phone, Cellular/Page Company written by Primary Care Provider (written on Primary Care Provider's stationery)

Date:			
Company			
Address			

Re: Parent's Name Address: Phone:

City, State, Zip

To Whom It May Concern,

I am the primary care provider for (Name of Child), who lives at (address, city, zip). (Name of Child) is a child with special health needs who requires the use of (type of equipment used).

Due to this child's special health care needs, it is medically necessary for the family to have uninterrupted gas services. Interruption of service could seriously jeopardize (Name of Child)'s health. Could you please assist them in developing a payment plan that will prevent any disruption of service?

Thank you for your attention and understanding in this matter. Please contact (name of contact) at (phone number and extension) if you have any questions.

Sincerely,

(name of Primary Care provider contact and company)

cc: name of parent/guardian

Requesting Supplies for Incontinence written by Primary Care Provider (written on Primary Care Provider's stationery)

Date:
Company
Address
City, State, Zip
Re: Name:
Address:
DOB:
Health Insurance Plan:
Plan ID#:
Pharmacy Name:
Pharmacy Phone:
To Whom It May Concern, I am the primary care provider for (Name of Child), who lives at (address, city, zip). (Name of Child) is a child with special health needs who requires the use of (type of supplies for incontinence needed).
This patient is incontinent as a result of (Name of Child)'s diagnosis. I therefore consider it medically necessary to prescribe diapers for at least three months. Could you please approved payment for these supplies.
Thank you for your help and attention to this matter. Please do not hesitate to contact (name of contact) at (phone # and extension) if you have any questions.
Sincerely,
(Name of primary care provider contact and company)
cc: (name of parent/guardian)
A signed and dated prescription will accompany this letter, including: Child's name, address, DOB, diagnosis, health insurance information, specific ID of prescribed item including amount per month, and estimate length of time item will be used.

Medical Necessity for Equipment written by Primary Care Provider (written on Primary Care Provider's stationery)

Date:
Company
Address
City, State, Zip
Re: Name:
Address:
DOB:
Health Insurance Plan:
Plan ID#:
Pharmacy Name:
Pharmacy Phone:
To Whom It May Company
To Whom It May Concern,
I am the primary care provider for (Name of Child), who lives at (address, city, zip). (Name of Child) is a child
with special health needs who requires the use of (type of equipment needed).
I consider it medically necessary for this patient to be equipped with (name of equipment needed) so that (reason
for use of equipment). This (name of equipment needed) will be required for at least three months.
tor use or equipment). This (name or equipment needed) will be required for at least timee months.
Thank you for your help and attention to this matter. Please do not hesitate to contact (name of contact) at
(phone # and extension) if you have any questions.
(in a contract of the contract
Sincerely,
(Name of primary care provider contact and company)
(taile of primary care provider contact and company)
cc: (name of parent/guardian)
A signed and dated prescription will accompany this letter, including:
Child's name, address, DOB, diagnosis, health insurance information, specific ID of prescribed item including amount
month, and estimate length of time item will be used.

per



Medical Necessity for Formula and Nutritional Supplement written by Primary Care Provider (written on Primary Care Provider's stationery)

(William St. Filmary Sale Freehalt Stationery)
Date:
Company
Address
City, State, Zip
Re: Name:
Address:
DOB:
Health Insurance Plan:
Plan ID#:
Pharmacy Name:
Pharmacy Phone:
To Milhorn It May Concorn
To Whom It May Concern,
I am the primary care provider for (Name of Child), who lives at (address, city, zip). (Name of Child) is a child with special health needs who requires the use of (type of formula and nutritional supplement needed).
I am writing to request your assistance in maintaining the continued health and growth of this patient, for whom (type of formula and nutritional supplement needed) is medically necessary for at least six weeks.
Thank you for your help and attention to this matter. Please do not hesitate to contact (name of contact) at (phone # and extension) if you have any questions.
Sincerely,
(Name of primary care provider contact and company)
cc: (name of parent/guardian)
A signed and dated prescription will accompany this letter, including: Child's name, address, DOB, diagnosis, health insurance information, specific ID of prescribed item including amount per
month, and estimate length of time item will be used.

ED Information

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Allergies

For EMT or ED pers	onnel				Baseline Data		
Child's SSN					Pulse rate	Site best taken	
					BP	Site best taken	
Parent/Guardian					Temp	Site best taken	
Address					Resp rate/minute		
					Oxygen saturation		
Cell Phone					Skin color		
					Best blood draw site		
Insurance					Pupils		
Policy #					Communication		
Policyholder Name					Preferred method	Language	
Primary Care Doctor			-		How child expresses p	oain	
					These things can upset or overstimulate my child (loud noises, bright lights,		
					medical equipment, separation from parents/special item, touch, etc.)		
Phone	Fax		Email				
Diagnoses							
					These things can help	calm my child	
Medications	Churcus make	D	· F	Time I act Oirean			
Name	Strength	Dosage	Frequency	Time Last Given			
	_						
		<u> </u>		<u> </u>			

Child's Name

Date Last Revised:

Contacts

The following are resources you may want to contact should you have any legal questions regarding your child's illness. In addition, your social worker/case manager may have other suggestions and resources.

Disability Rights Network (DRN)

Harrisburg Office

1414 N. Cameron Street, 2nd Floor Harrisburg, PA 17103 Voice 1.800.692.7443 TDD 1.877.375.7139 Voice 717.236.8110 TDD 717.346.0293 Fax 717.236.0192 Email drnpa-hbg@drnpa.org

Philadelphia Office

The Philadelphia Building 1315 Walnut Street, Suite 500 Philadelphia, PA 19107–4798 Voice 215.238.8070 Fax 215.772.3126 Email drnpa-phila@drnpa.org

Pittsburgh Office

429 Fourth Avenue, Suite 701 Pittsburgh, PA 15219-1505 Voice 412.391.5225 Fax 412.467.8940 Email drnpa-pgh@drnpa.org

Education Law Center

Philadelphia Office Phone 215.238.6970

Pittsburgh Office
Phone 412.258.2120



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Child's Name

Date of Birth

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