

# Information Guide for Families and Caregivers of Children with Trachs



## TrachCare

---

Edited by Josephine Cheung, Shiufun Cheung,  
Leslie Gaffney, Sue Wachta and Erin Ward

# Table of Contents

Tips	
Tips for Families of Children with Trachs.....	1
Parenting Challenges.....	3
Tracheostomy Books and Videos.....	6
Getting Ready for Discharge from the NICU.....	7
Steps to Take if Nursing Is Needed.....	8
Pictures and Illustrations	
Tracheostomy Attachments .....	9
Decannulation .....	10
From Tracheostomy to Decannulation: A Journey .....	10
Resources in Massachusetts	
Important State Agencies and Resources in Massachusetts.....	11
Family Support Organizations: Trainings and Conferences.....	12
List of Private Duty Nursing (PDN) Home Health Agencies.....	14
List of Personal Care Attendant Agencies.....	16
Essays	
Welcome to Holland.....	19
Celebrating Holland.....	20
On Being a Patient.....	21

---

## FROM THE EDITOR

Taking care of children with trachs is challenging. As parents, caregivers and healthcare providers, we often find ourselves scrambling for the right resources. Sometimes we feel alone. What we would have given to receive a little guidance from people who have been there.

In the following pages, we have collected information that the founders of this group feel are the most useful. People were consulted, websites culled, and articles borrowed. We hope the result will enable you and your child to receive the best of care. (October 2009)

## ACKNOWLEDGMENTS

The information in this guide was compiled by Josephine Cheung, Linda Concheri, Leslie Gaffney, Julie Leahy, Erin Ward and Sue Wachta.

---

**TrachCare, Inc. PO Box 550075 Waltham, MA 02455**

**[www.trachcare.org](http://www.trachcare.org) | [info@trachcare.org](mailto:info@trachcare.org)**

## Tips for Families of Children with Trachs

The “Tips” on these pages are gathered from parents of children with trachs who would like to share their experiences. As the need for every child is different, always consult your child’s doctors, nurses, therapists, and teachers before using any information presented for the care and treatment of your child. We would also like to share three important tip pages obtained from the Internet: “Parenting Challenges” from [www.tracheostomy.com](http://www.tracheostomy.com), “Getting Ready for Discharge from the NICU” and “Steps to Take if Nursing is Needed” from [www.carepoints.org](http://www.carepoints.org).

### *You and Your Child*

- Trust your parental instincts. Take cues from your child. You do know your child best and what is best for your child.
- Allow your child to be a child first. It is easy to let the medical care and treatments take over your daily lives. Make a point to schedule fun time with your child.
- Appreciate the small things your child does. It does wonders for you, as a parent, to enjoy the smaller, less obvious accomplishments in life.
- As hard as it can be, carve out one-on-one time for your other children.
- Schedule relaxation time for yourself and also relaxation time with your spouse, partner, and/or friends.
- When other children approach your child with questions about his trach, embrace them and encourage the children to ask the questions. Adults are typically nervous and may react by drawing them away. Let the adults learn from their children. Help them learn about trachs and children with trachs and how it is just a different way of breathing. We are all more similar than different.

### *Working with Your Team*

- Everyone has the best of intentions for your child. Work with the team and never think of anyone as your adversary.
- When in doubt, ask and clarify with your child’s care-taking, educational and medical team. Do not assume. No question is too silly or unimportant.
- Do your homework by searching online or asking someone who has been there. Knowing what you are talking about really helps when working with supply companies, insurance companies, caregivers, therapists, nurses and doctors.
- Spend time to work with your child’s caretakers. Discuss your child-rearing philosophies and expectations and come to an agreement with your team. It is important to keep an open mind during discussions, but an agreement needs to be reached to maintain consistency for your child.
- Start early to develop an organization process that works for you. At first, it may be easy to remember all the information. As time passes, relevant dates and salient details multiply at a rapid rate. Having an information input system in place is extremely helpful.
- Before you go to a meeting, jot down questions you want to ask and points you want to clarify. If it is helpful, hand out notes. Include your child’s picture in the notes if your child will not be present.
- Use a camcorder to record any infrequent medical occurrences or occurrences that are hard to describe. “A picture is worth a thousand words.”
- Make time to say thanks to those who have gone out of their way for your family.

### *Building Relationships*

- Build good relationships with your child’s caretakers, healthcare providers, therapists, teachers, staff and administrators at school. As Leslie Seid Margolis, Esq. from Maryland Disability Learning Center ([www.Wrightslaw.com](http://www.Wrightslaw.com)) writes: “Good relationships will generally ensure that issues you bring up will be taken seriously. Do not complain about every issue that comes up ... This is the equivalent of crying wolf, and ensures that when a serious issue does arise, you will not be taken seriously.”
- Make friends with a therapist or a nurse at your medical supplies company. They are great resources to help you find the right equipment.

### *E*mergency Contacts

- Put a list of emergency phone numbers in a visible place, preferably near the phone. Make sure frequent visitors know where it is. It will give you peace of mind.
- Make sure the local rescue squad knows you have a child at home with a trach. They usually keep a list of children with special medical requirements. Be sure to touch base with them annually.
- Discuss with your doctor to get a referral to obtain a handicap placard for your car when traveling with your child.
- Make sure the electric company has your home listed on their medical emergency list. They keep a list of homes with life-sustaining medical equipment. Call them as soon as there is a power outage. Don't assume that they already know. Let them know you are on the list and that you have medical equipment upon which your child depends. If possible, you will get priority service. They will also keep you posted of their progress.

### *M*edical Procedures

- Follow universal precautions, particularly when the caretaker is sick. A mask should be worn and hands washed frequently.
- Use non-split 4x4 sponges to clean delicate areas like the eyes, nose, mouth, and around the trach area. They are soft and absorbent. You can get these from your medical supplies company.
- Always tell your child before suctioning to reduce anxiety.
- If your child has a g-tube, tape the med-port at night to avoid accidental opening and leaking all over bed.
- Discuss with your child's pediatrician to see if flu shots and synergis are recommended. Synergis is a vaccine against the respiratory syncytial virus (RSV), a virus that can cause bronchiolitis.
- If you can, provide breast milk for your child in the best way you can. According to the editors of Prevention Magazine in *Food and Nutrition*, one of a series of health books: "Early breast milk contains substances that bolster a baby's immune system to help fight off allergies and infections."

### *E*quipment and Supplies

- Be relentless and persistent in pursuit of your child's healthcare or technology needs and supports. The "squeaky wheel does get the grease."
- Keep a non-cordless phone in your home that does not require AC power to work. In the event of a power failure, cordless phones won't work.
- Carry a cell phone with you at all times when away from home.
- Invest in a stroller that has a sturdy and roomy storage space for your equipment. A double stroller can provide the space and the convenience you need. You can use the front seat for the suction machine and the back seat for your child.
- Put a roll of paper towels in EACH bathroom and near the kitchen sink. Use paper towels instead of dishcloths, facecloths, guest towels, or hand towels. This practice will help prevent the spread of germs.
- Put a bottle of hand sanitizer and a box of tissue paper in EVERY room of your house, in the car and in your diaper bag, etc. Have everyone use them frequently.
- Make sure you have a "To go bag" with all the essential trach supplies that you need in case of an emergency: spare trach, one trach a size smaller, scissors, extra trach ties, ambu bag, etc.
- Invest in a video-enabled baby monitor as the cry of a child with trach is often soft or not audible. These monitors work well even in a dark room.
- You can now easily put your child's vital medical information on a flashdrive and carry it with you at all times. Be sure to update frequently.
- Put your monthly order schedule on your calendar. The calendar will remind you when to place your order.

## Parenting Challenges *(This page updated 04/17/08)*

No job is more challenging or more rewarding than parenthood. The challenges and often the rewards too are even greater when your child has special needs.

### *Some Problems You May Face When Your Child Has a Trach and/or Other Medical and Long-Term Issues*

Feeling a multitude of uncomfortable emotions such as helplessness, anger, fear, guilt, depression, confusion, sadness, jealousy and shame. These are all normal reactions to the loss of a “normal” child. Some may last a few weeks, while others can linger for years. All parents go through a grieving process when they learn their child needs a tracheostomy. But the process itself is very individualized.

- Overall increased STRESS
- Difficulty learning to care for your child and feelings of inadequacy
- Financial burdens
- Problems and red tape with insurance companies, equipment vendors, medical staff, nursing agencies, government agencies and community organizations.
- Home accessibility problems and limited space for equipment and supplies
- Marital problems
- Sibling anger, jealousy and resentment
- Danger of over-protecting the child with a trach
- Your child may be teased or feel different because of the trach
- Loss of privacy
- Loss of sleep
- Social isolation
- Overwhelming number of doctor's appointments, therapies and surgeries
- Problems obtaining services through special education
- Family and friends may not understand how much extra work, time and stress is involved in raising a child with a trach.
- Job issues: needing more time off and flexibility
- Discrimination toward people with disabilities

### *Some Suggested Techniques to Help Minimize These Problems*

- When your child has a new trach, spend time caring for your child in the hospital before discharge, so that you will be more comfortable with homecare.
- Train other family members or friends to care for your child in case of an emergency or if you need a babysitter.
- Take care of yourself and arrange regular breaks (respite). Your rest is very important. Your child may suffer if you are overwhelmed with stress and responsibility.
  - [National Respite Locator Service](#)
- Take time for hobbies.
- Network and talk to other parents dealing with similar issues.
  - [Trach-ties](#)
  - [Tracheostomy Message Boards](#)
- Get on-line access, if possible, for research, information and networking.
  - [Tracheostomy Resources](#)
- Join a local support group.
- Choose your battles wisely and prioritize. This is especially true when dealing with special education problems.
- Understand that your child has a legal right to an appropriate public education. In order for your child to be safe at school, he/she must have a person trained in tracheostomy care (preferably an RN or LPN) with him/her at all times. Work with your school to assure that your child is safe at school and during transport.
  - [School Nursing Services for Special Children](#) Legal information by By Phil Stinson, Esq.
  - [Medical Services: The Disputed Related Service](#) Journal of Special Education, Winter, 2000, by Larry Bartlett
  - [Policy for Tracheostomy Care and Suctioning in the School Health Setting](#), Courtesy of Escambia County Health Department-school
  - [Macon boy, 3, collapses at school, dies at hospital](#)

- Bring someone with you to take notes at Individual Education Plan (IEP) meetings. If this is not possible, ask if you can tape record the meeting (this may be uncomfortable for some).
- Allow and encourage siblings to express their feelings.
  - [The Sibling Support Project](#)
- Treat your child as normally as possible. Set limits and discipline your child as you would if the child did not have a trach.
- When in doubt or for any major medical procedure, get a second opinion.
- Do your own homework regarding your child's condition. Do not assume that the medical professionals know what is best for your child or that they have all the answers.
- You are the most important person in your child's life, and you are an equal part of your child's medical team. Be your child's advocate.
- Find a pediatrician experienced with children with special needs who will work with you in coordinating your child's care and other medical specialists.
- You have the right to approve or disapprove of a nurse or nursing agency. Having nurses in your home is a difficult adjustment, try to have reasonable expectations.
- There is a huge discrepancy in the amount of skilled nursing care that a child with a tracheostomy should receive. In the U.S., children with tracheostomies average 8 hours per day of home nursing. This amount increases to 16 hours if the child is also on a ventilator. These are very general guidelines and vary depending on the individual child's needs. Some families would rather not have nurses in their home; others cannot manage without home nursing. The important issue is safety. If you feel that you cannot safely care for your child 24 hours a day, then it is reasonable to insist on home nursing for a child with a tracheostomy.
- SPEAK UP: do not be afraid or embarrassed about asking questions or asking for help.
- There is nothing wrong with asking for help. To quote parent of a child with a trach, "Children with special needs have parents with special needs."
- Keep organized with a "Things-To-Do" list.
- Keep an updated calendar for appointments, doctors appointments, therapies, start dates of medications, when to order supplies, etc.
- Make a checklist of critical items to take with you when traveling away from home.
- Do a weekly inventory and keep back-up supplies to avoid running short of equipment.
- [Financial Assistance for Kids with Tracheostomies](#) by Kathy Rowe
- Call government agencies such as the Department of Public Health and the Department of Public Welfare to find out what programs are available in your state.
  - [SSI](#)
  - [Medicaid](#)
  - [Medicaid Waiver Programs](#)
- Contact local charitable organizations such as Lions, Knights of Columbus, Kiwanis, and Church groups for help with items not covered by insurance (such as ramps, lifts and other home adaptations).
- Contact groups such as [United Cerebral Palsy Association](#), [Easter Seals](#), and the [March of Dimes](#) for special programs that might benefit your child.
- Take advantage of opportunities to educate the public about the value of children with special needs to help lessen ignorance and discrimination.
- Communicate with your spouse, listen to each other and make a date with your spouse!
- Plan special activities and private times with siblings.
- Keep a sense of humor:-)
- Seek outside professional help if needed for emotional support.

### *T*ips when Working with Doctors

- Find a doctor you are comfortable working with
- Find a doctor with a "Family Center" approach
- Work together as a team
- Recognizing each others expertise
- Realize that doctors are human
- Get a second opinion when needed
- Be organized for appointments

## Tips for Physicians and Nurses

 Dear Future Physician, an open letter by Ann Schrooten  
([http://www.tracheostomy.com/networking/parent/future\\_physician.htm](http://www.tracheostomy.com/networking/parent/future_physician.htm))

*Things to keep in mind when working with families of kids with special needs:*

- Parents are looking for answers
- They have experienced a loss. They are replacing their dreams of one child for the realities of another.
- Avoid making predictions about the outcome of a specific case.
- Give general advice, but caution that nobody can predict how a child will turn out.
- Some parents are receiving ill-timed or poor advice from a multitude of people
- Parents need not face everything at once there is a difference between refusing to accept and needing some time to accept.
- They may be feeling guilt, depression, anxiety, etc.
- Parents often feel isolated and alone; as if they were the only family having a child with special needs.
- Do refer parents to a parent support group. This will save you a lot of questions as well.
- They are probably not aware of special education programs and services that may be available to them in their community.
- They want to talk
- They need someone to listen

## Home Nursing

- Parents Concerns Regarding Home Care Nurses  
- Quotes from Parents using home nursing.  
([http://www.tracheostomy.com/misc/home\\_nursing.htm](http://www.tracheostomy.com/misc/home_nursing.htm))

## Family Centered Care

- Family Centered Care Tutorial  
(<http://www.tracheostomy.com/misc/fcc/index.htm>)
- Institute for Family-Centered Care  
(<http://www.familycenteredcare.org/>)

## Essays (<http://www.tracheostomy.com/misc/essays/aaron.htm>)

- Aaron Needs a Tracheostomy by Richard and Cynthia Bissell
- "Welcome to Holland" by Emily Pearl Kingsley
- Letter to Trisha from Trisha's Grandma
- The Night that Changed Our Lives by Deb, Connor's mom
- One Night at the Bissell's by Richard Bissell
- Helping Parents Cope with a High-Risk Birth: Terror, Grief, Impotence, and Anger by Michael T. Hynan, PhD.
- Families at Risk: Quality of Life in Technology-Dependent Children and their Families by Dennis J. Baumgardner, MD
- Welcome to My Home... I Think By Sharon Burlison

## Tracheostomy Books

(<http://www.tracheostomy.com/resources/books/index.htm> updated 8/26/2007)

- **Pediatric Tracheostomy Home Care Guide**  
by Cynthia M. Bissell, RN  
Jones and Bartlett Publishers, 2007
- **Just Like You** by Emily Dunafin
- **Growing and Thriving with a Tracheostomy**  
Book and Video now available  
Ann Marie Ramsey, MSN, RN, CPNP  
Colin Macpherson, MA, CCLP  
Department of Pediatric Otolaryngology  
University of Michigan Medical Center
- **The Care of Children With Long-Term Tracheostomies**  
by Ken M., Ph.D. Bleile (Editor)  
List: \$45.00  
Published by Singular Pub Group  
Publication date: July 1993
- **Care of Your Tracheostomy : A Patient Guide**  
by Tracheostomy Teaching Committee  
List: \$8.00  
Published by Catholic Health Assn.  
Publication date: July 1987
- **A Guide to Pediatric Tracheostomy Care**  
by Pat Adamo  
List: \$27.95  
Published by Charles C Thomas Pub Ltd  
Second Edition, 1993
- **Living With Your Tracheostomy**  
List: \$7.95  
Published by Center for Learning, Jan, 1993
- **Tracheostomy and Artificial Ventilation in the Treatment of Respiratory Failure**  
by Stanley A. Feldman  
List: \$17.50  
3rd Edition  
Published by Krieger Publishing Company, June 1977
- **Tracheostomy Care Manual**  
by Howard Levine, Connie Miller  
2nd Edition  
Published by Thieme Medical Pub, April, 1988
- **Tracheostomy for the Nurse**  
by F. Wilson  
Published by Edward Arnold
- **Tracheotomy (Sipac)**  
by Johannes J. Fagan (Editor)  
3rd Edition  
Published by Amer Academy of Otolaryngology,  
January 1997
- **When Your Child is Technology-Assisted**  
A home care guide for families  
by Paul Kahn
- **Shiley® Pediatric Tracheostomy Home Care Video**  
[www.mallinckrodt.com](http://www.mallinckrodt.com)  
Mallinckrodt, Inc.  
P.O. Box 5840  
St. Louis, MO 63134  
1-888-744-1414
- **Tracheostomy Care Handbook** from Cincinnati Children's Hospital Medical  
(<http://www.tracheostomy.com/resources/pdf/tracheotomymanual.pdf>)
- **Suggested Equipment List** from Cincinnati Children's Hospital Medical  
(<http://www.tracheostomy.com/resources/pdf/tracheotomyequipmentlist.pdf>)

## Getting Ready for Discharge from the NICU:

(content may also be helpful for children or youth being discharged from the PICU (Pediatric ICU) or MICU (Medical ICU))

Before you know it, hopefully it will be time to bring your baby home. There are usually three routes to discharge in the NICU...going directly home, going to a floor within the hospital for additional training and going to a sub-acute facility for further rehabilitation and additional training. If your child is being transferred to another floor in the hospital or to a sub-acute facility, ask the staff to explain the differences. Transition out of the NICU can be difficult. Many times it is hard for families to leave the NICU where the baby was under constant watch. But as the baby becomes more stable and the families become more comfortable with their child's care many times NICU care is no longer needed. Before discharge, family members should make sure they are comfortable with all aspects of care and spend time caring for their baby on their own. Families should also be comfortable knowing what can happen if they go home and then need to be readmitted. Will the baby need to go through the ER? Will they be admitted back to the NICU or will they have to go to the PICU (Pediatric Intensive Care Unit)? What are the differences between the NICU and the PICU?

Most NICUs are only for babies who have never been discharged. However, some NICUs will readmit but require the infant to be in an isolation room so that outside germs are not brought into the NICU. If the hospital's policy is not to readmit into the NICU, the baby will go to the PICU. PICUs care for children from birth until age 22. Some hospitals may also have a separate Cardiac ICU for infants and children with heart conditions.

The following is a checklist that will help in the discharge process. As the discharge nears, the NICU team (doctors, nurses, social worker, discharge planner etc.) will help to ensure that everything is in place.

- If the NICU team has determined that nursing is needed for your child to be cared for at home, has the discharge planner contacted MassHealth Community Case Management who will assist in determining your nursing eligibility?
- Have you contacted nursing agencies directly (this can help in the process)?
- Do you know what your insurance coverage is for nursing, durable medical equipment etc.?
- Has the discharge planner contacted your insurance company for pre-approval for equipment and nursing care that will be needed at home?
- Has the discharge planner or the social worker explained supplemental insurance programs in the state where you are located? In Massachusetts this falls under MassHealth. Common Health and Kaleigh Mulligan can help pay for co-pays and equipment/nursing if your primary insurance doesn't cover these items. See the agency section for more information.
- If your child doesn't have insurance, ask the social worker if your state has programs that you may be eligible for? In Massachusetts, the program is MassHealth. See the agency section for more information.
- Have you and the discharge planner contacted the Early Intervention (EI) program in your area (assessments must be within 45 days of referral). Early intervention will provide Physical Therapy, Occupational Therapy and other services if your child is found eligible. EI Programs encourage families to call and self-refer. To find out what program serves the town that you live in call 1-800-905-TIES, the central directory number for EI in Massachusetts or check the website at [www.massfamilyties.org](http://www.massfamilyties.org) and see the link Early Intervention Directory.
- If your child is medically complex, once they are enrolled in Early Intervention, ask about the Regional Consultation Program in your area and have your EI case manager refer your child to this program. Please see agency section for further details of this program, which can help with respite, equipment etc.
- Ask the hospital and Early Intervention if they are aware of support groups, Internet resources, books etc. that might help to understand your child's condition. If your child is undiagnosed, ask if there is any condition that is similar with the same issues that you are dealing with.
- Have other agencies been identified as potential help (Department of Developmental Disabilities, Department of Public Health, Mass Commission for the Blind, Mass Commission for the Deaf and Hard of Hearing etc.) and have they been contacted? See agency section.
- Has the family been trained in CPR?
- Has an emergency plan been established at home?
- Do you have a "To Go" bag with all the essential trach supplies you would need in an emergency?

- Is it necessary to contact local Fire/Police Departments to inform them about your child's condition so that they will be prepared to attend to your child according to your wishes in the event of an emergency? What will happen if you call 911? How long will it take? What hospital will they bring your child to? Are there any exceptions? You may want to have your doctors contact the local hospital so that they are aware of the situation.
- What equipment is needed at home (ex. Apnea monitor, heart monitor, oximeter, oxygen etc.)? Has the equipment been ordered?
- How will you transport your child? Do they need a special car seat or a car bed? Where can you find those?
- Do you feel comfortable with all aspects of your child's care? What training do you need to go home (g-tube feedings, tracheostomy care, wound care etc)?
- What follow up appointments are needed? How do you make appointments? How do you find specialists? When should you make these appointments for (1 week, 1 month etc.)? Is there a service in the hospital like Coordinated Care that helps with medically involved children? Are there special neonatal follow-up clinics?
- What should you watch for? What are the guidelines for returning to the hospital Emergency Room (limits on oxygen levels or heart rates might be established as benchmarks)?
- If your child is going to need future surgeries, at about what age might those occur and who will perform the surgeries?
- Has the community pediatrician been notified about discharge? If you don't have a pediatrician yet, ask if anyone has recommendations. Some practices specialize in children and youth with special need

## Steps to Take if Nursing Is Needed

As you approach discharge from the hospital, the NICU or ICU team (doctors, nurses, social worker, discharge planner, etc.) will determine what will be necessary for your child to go home. In some cases where a child has complex medical needs (tracheostomy, g-tube, seizures, ventilator, TPN etc.) nursing is needed. The following may help you to secure nursing for your child.

- **Determine Coverage:** Find out what insurance coverage you have (visiting nursing visits, skilled nursing visits or block nursing and if there are yearly or lifetime caps). All policies are different and many of the private insurers have limited home nursing available.
- **Apply for Supplemental Coverage:** If your insurance has limited nursing coverage, in Massachusetts, MassHealth will cover nursing if medically necessary. It can take up to 90 days to process a MassHealth application so apply as soon as it is determined that your child will need it. Depending on your situation, you may qualify for various MassHealth programs. Common Health is a supplemental insurance program for individuals with special needs (a premium is paid based on income). Kaleigh Mulligan Home Care is a waiver program for children with complex medical needs who either require technology and/or skilled nursing care in order to live at home. This program is called a waiver program because family income is not used to determine eligibility. Please see other sections in this packet for more details on MassHealth.
- **MassHealth Community Case Management:** If home nursing is approved by MassHealth, you will be assigned a MassHealth Community Case Manager who will do a nursing assessment, help determine hours of eligibility, and will assist in providing information about possible nursing resources. You can read more about this Community Case Management program for complex health needs at: <http://commed.umassmed.edu/services/care-management/case-management> .
- **Call Nursing Agencies in Your Area:** Talk to the hospital discharge planner and your Community Case Manager through MassHealth to find out what agencies cover your area and ask them to call the agencies early in the process. In addition, it can help if you call directly and explain your situation. The sooner you start looking, the sooner you will find help. Be flexible. If they can't fill the exact hours that you would like, try what they can offer and work into what you would like down the road. Be persistent. With a nursing shortage, it is hard to fill hours but it can be done and many nurses enjoy working with infants and children at home

## Tracheostomy Attachments

A tracheostomy tube provides direct and uncompromised access to a child's airway, however, it is often not sufficient on its own to sustain breathing indefinitely. In most cases, other attachments or machines are required.

The most common function among these attachments is humidification of the airway. When we breathe through our noses and mouths, air is naturally warmed, moistened and filtered. These mechanisms are bypassed for children with trachs. Without humidification, secretions thicken, potentially leading to mucus plug. For this reason, it is essential to provide adequate humidification to keep secretions thin. The attachments shown below, whatever their primary function, all maintain humidity of the airway.

In other cases, a child will require mechanical assistance, such as continuous positive airway pressure (CPAP), bilevel positive airway pressure (BiPAP), and mechanical ventilation. The use of these machines is not confined to trached patients, but they are commonly seen in trached patients.

- Photo (a) shows a child using a humid-vent mini humidity moisture exchanger (HME), also called the Swedish nose or artificial nose. Placement of

an HME over the open trach allows air to stay warm, moist and clean.

- Photo (b) shows a child wearing a Portex Thermovent T HME.
- Photo (c) shows a child wearing a Passy-Muir speaking valve, which leads to increased vocalization. The one-way valve only allows air inflow. It can therefore also be used to train children to breathe through their mouth and nose.
- Photo (d) shows a child wearing a trach mask or trach collar directing a fine mist of moisture to the trach. It is used while a child is sleeping or during waking hours when mucus is dry. The fine mist is delivered by an air compressor either with or without heating.
- Photo (e) shows a child with a mechanical ventilator, a machine that generates a controlled flow of gas into the airway, allowing for proper gas exchange.
- Photo (f) shows a child, without a trach, wearing a nose mask connected to a CPAP/BiPAP machine. The CPAP/BiPAP machine provides positive air pressure to help keep open the breathing passage of patients suffering from obstructive sleep apnea.



a. HME or Swedish nose



b. Portex Thermovent T



c. Passy Muir valve



d. trach mask (mist)



e. ventilator



f. CPAP/BiPAP

## Decannulation

There is no schedule or predetermined time frame for how long a child will need a trach; it is as different as each child is different. In some cases the child will always need to have a trach and/or ventilatory support.

The removal of the tracheostomy tube is clinically referred to as decannulation, literally “removal of a cannula.” Decannulation is not lightly undertaken and should be attempted only in a hospital setting under the care of an otolaryngologist. In most cases, sleep studies in the hospital setting are ordered beforehand, and only after downsizing of the tube or a long period with the tube capped. Among the things to be considered are whether the original airway obstruction is resolved, whether airway secretions are under control, and whether mechanical ventilation is no longer necessary. Predictors of success include the ability to produce a vigorous cough and the absence of aspiration.

Some procedures for decannulation (<http://www.tracheostomy.com/decan.htm>):

- Simply remove the tube. If the stoma (hole) does not close by itself, a minor surgical procedure may be needed.
- Place a smaller tube and plug the tube for increased amounts of time. When the child is tolerating the plug 24 hours a day, then the tube can be removed. Note: A speaking valve may be used as a transitioning tool between an open trach tube and plugging for decannulation. This allows for the child to transition to using the upper airway for exhalation, reintroducing airflow and sensation and easing the anxiety often associated with plugging.
- Include the decannulation as part of a reconstructive procedure
- Surgical decannulation (when repair of the trachea around the tube is needed).

## From Tracheostomy to Decannulation: A Journey

The following illustrates one child’s journey from tracheostomy to decannulation.

- Photo (a) illustrates the child at 7 weeks old, 5 weeks after a tracheostomy tube was placed.
- Photo (b) illustrates the use of an HME during waking hours.
- Photo (c) shows the use of Passy-Muir speaking valve, allowing for vocalization.

- Photo (d) was taken one hour after decannulation. The patient is still in the hospital under the care of an otolaryngologist. The stoma is clearly visible.
- Photo (e) illustrates the presence of the trach stoma of this child one year after decannulation. The stoma, though small, was not yet closed. Surgical closure for this child has not been performed because of continual concern of small airway.

**a. trached infant**



**c. speaking valve**



**e. trach free**



**b. humidification filter**



**d. decannulation**

## Important State Agencies and Resources in Massachusetts

Most of the following has been compiled from information provided by the *Family TIES of Massachusetts: Resources for Families of Children with Special Needs* for the purpose of developing a reference guide of specific state agencies and resources that may be of particular interest to families and caregivers of children with trachs. To obtain the Family TIES Directory, call 1-800-905-8437 or access online from <http://www.massfamilyties.org>.

### **DEPT. OF PUBLIC HEALTH (DPH)**

**1-800-882-1435** [www.mass.gov/dph](http://www.mass.gov/dph)

#### **Community Support Line**

**1-800-882-1435**

A community support line that provides information and technical assistance on state resources for children with special healthcare needs.

#### **DPH Care Coordination for Children with Special Health Care Needs**

**Main number: 1-800-882-1435**

Care Coordinators work with families to assist in coordinating agency services to meet special needs. Families who are experiencing difficulty obtaining and coordinating services may be eligible.

#### **Early Intervention (EI)**

**1-800-905-8437**

An integrated developmental service available to families of children from birth to 3 years of age who have, or are at risk for having, developmental delays.

#### **Regional Consultation Programs (RCP)**

##### **Contact your EI Service Coordinator**

RCP can provide additional support for children in the EI program with significant healthcare and developmental needs. Some of these include respite funding, parent trainings, assistive communication support, and specialized staff support.

#### **Catastrophic Illness in Children Relief Fund**

**1-800-882-1435** [www.mass.gov/cicrf](http://www.mass.gov/cicrf)

A fund that may help provide financial assistance to families who have medically related needs expenses not covered by private insurance, federal, or state healthcare assistance.

#### **Pediatric Palliative Care Network**

**1-800-882-1435** [www.mass.gov/ppcn](http://www.mass.gov/ppcn)

Services for children under 19 with a wide range of life-limiting diagnosis. Services are to improve the quality of life of the child by meeting physical, emotional, or spiritual needs.

#### **Massachusetts Department of Developmental Disabilities (DDS) Family Support Programs**

**1-888-367-4435**

Regional Family Support Programs for children with complex healthcare needs for individuals who are approved for DDS services.

### **MASSACHUSETTS DIVISION OF MEDICAL ASSISTANCE (DMA) -MASSHEALTH**

**1-800-497-4648** [www.mass.gov/masshealth](http://www.mass.gov/masshealth)

#### **MassHealth Enrollment Centers**

**Main Number: 1-888-665-9993**

Revere: 1-888-665-9993

Springfield: 1-800-332-5545

Taunton: 1-800-242-1340

Tewksbury: 1-800-408-1253

A Medicaid program that provides comprehensive health insurance or help in paying for private health insurance to low- or medium-income people living in Massachusetts.

#### **Common Health**

**1-800-841-2900**

A primary or supplementary low cost insurance for children with disabilities whose families do not meet the income level requirements to be eligible for MassHealth.

#### **Kaleigh Mulligan Program**

**1-800-408-1253**

A waiver program for children with complex medical needs who either require technology and/or skilled nursing care in order to live at home. This program is called a waiver program because family income is not used to determine eligibility. However, the child's financial resources will be evaluated. Nursing is determined based on medical needs.

#### **Masshealth Standard/Commonhealth Premium Assistance -MSCPA**

**1-800-862-48-40**

A program that helps pay for personal cost of private health insurance for individuals or families who get MassHealth or CommonHealth when it is found to be cost effective for the State.

#### **Community Case Management Program (CCM)**

**1-800-842-9375**

A case management program for children within Massachusetts who require home care nursing services. Call the number to obtain information about coverage determination.

## Family Support Organizations: Including Trainings & Conferences

The following is a list of family support organizations, some that offer trainings and host conferences for families. They provide great opportunities for parents to make connections and learn advocacy skills needed to care for children with trachs.

### **TrachCare, Inc.** **www.trachcare.org**

The Massachusetts-based non-profit, that has developed this guide, and is dedicated to helping provide support, education, and awareness to families with children and young adults who have, or previously had a tracheostomy. We host family gatherings, often collaborative with medical professionals working to improve tracheostomy care through educational forums, maintain a website and informational guide. You may join our e-mailing list to stay contacted and visit our website to register.

### **Aaron's Tracheostomy Page** **www.tracheostomy.com**

An excellent and comprehensive Internet resource on tracheostomies created by a mother and a registered nurse of children with special needs.

The mission of Aaron's Tracheostomy Page is: To help assure the highest quality home care for children with tracheostomies; provide needed tracheostomy information in order to ease some of the anxiety related to caring for a child with a trach; and to facilitate parent-to-parent networking and support.

### **Global Tracheostomy Collaborative (GTC)** **www.globaltrach.org**

A multidisciplinary team of physicians, medical professionals, patients, and families around the world working to improve the quality of global tracheostomy care. Patients and families are invited to visit the website, sign up for a free patient-family membership to follow the ongoing GTC efforts, and are welcome to submit their tracheostomy story to help spread awareness.

### **DEVELOPMENTAL DISABILITIES COUNCIL** **617-770-7676 www.mass.gov/mddc**

#### **Consumer Empowerment Funds**

A funding resource to provide individuals with developmental disabilities or their family members to attend conferences or trainings. The goal is to promote empowerment by assisting training efforts for families. Each family can receive up to \$500 per event per year.

### **Federation for Children with Special Needs (FCSN)** **1-800-331-0688|www.fcsn.org**

A center for parents and parent organizations to work together on behalf of children with special needs and their families. The FCSN comprises of several family advocacy, education, and training organizations. Some of these are Family TIES, Mass Family Voices, Parent Training and Information Center, and many more.

#### **FCSN Annual Conference (March)**

A statewide annual conference attracts over 500 parents and professionals.

### **Family TIES of Massachusetts: Together In Enhancing Support**

**1-800-905-8437|www.massfamilyties.org**

A statewide information and support network provided by and for families of children with special needs. It offers a "parent-to-parent" program where a coordinator matches a parent to an appropriate support parent. A "support parent" is someone who is trained to listen, share concerns, offer information and support, with respect for confidentiality, cultural and individual differences. Family TIES also publishes a "pink" resource directory annually to help parents locate services and resources for their children with special needs. The directory is available at the above website. Family Ties also offers skill-building workshops to support families of children and youth.

### **Massachusetts Family Voices** **1-800-331-0688 |www.fcsn.org/mfv**

The state chapter of a national organization of parents and professionals who are committed to improving systems of care for children with special healthcare needs. Mass Family Voices has an excellent website and a "Listserv" where parents and professionals can share information and resources easily and efficiently. Mass Family Voices have also hosted a series of topical conference calls that may be helpful resources for families stored on their website.

---

**MASSTART: Massachusetts Technology Assistance Resource Team**

978-851-7261 x4022

<http://www.mass.gov/eohhs/docs/dph/com-health/special-needs/masstart-brochure.pdf>

An important consultation service for families of children with trachs or other technology-dependent healthcare needs. The program, sponsored by DPH, helps families and schools work together to develop individualized healthcare and emergency plans and provides training for school staff members.

**Parent Training and Information Center (PTI)**  
1-800-331-0688/[www.fcsn.org](http://www.fcsn.org)

A program that offers parental training to develop advocacy skills necessary for improving the quality of special education services for your children.

**PTI Educational Trainings (Ongoing)**

***“Turning Three”*** A workshop to help prepare for the transition from Early Intervention to the public special education process at age three.

***“Basic Rights”*** An introductory workshop on special education law and student rights.

***“An IEP for My Child”*** A workshop to learn how to write an appropriate “Individualized Education Plan” for your child.

**Early Intervention Parent Leadership Project (EI PLP)**1-800-353-4757/[www.eiplp.org](http://www.eiplp.org)

An organization for parents of children who receive Early Intervention services from birth to age 3. Our TrachCare project evolved out of a parent grant from the EI PLP. The PLP is sponsored by the Department of Public Health (DPH).

**Massachusetts Families Organizing for Change**  
1-508-824-6946 [www.mfofc.org](http://www.mfofc.org)

A grassroots organization that provides leadership training to help inform and educate individuals, families, and the community about advocacy, services, and resources for individuals with disabilities.

**Mass Families Organizing for Change Annual Training: (Regionally based)**

***“Mass Families Organizing for Change Leadership Series”***

A leadership series to connect with other families and learn lifelong advocacy skills. The training is held over three weekends.

## List of Private Duty Nursing (PDN) Home Health Agencies

Finding nurses to work in your home to fill your approved nursing hours may pose a challenge for many. This list provides agencies in Massachusetts that you can contact directly.

PDN Home Health Agency	Address	Phone
Centrus - Franklin	38 Pond St., Ste 105, Franklin, MA 02038	508-528-3090
Centrus - Newton (formerly Maxim)	1320 Centre Dr., Ste 303, Newton Center, MA 02459	877-606-2946
Centrus - Plymouth	225 Water St., Ste A 150, Plymouth, MA 02360	800-698-8200
Centrus - West Springfield	30 Capitol Dr., Ste C, West Springfield, MA 01089	866-547-2782
Centrus - Wilmington	226 Lowell St, Suite A3, Wilmington, MA 01887	978-658-3092
Centrus - Worcester	130 Elm Street, Suite 100, Worcester, MA 01609	508-754-8205
Excel Homecare Services, Inc	185 West Avenue, Suite 103, Ludlow, MA 01056	413-583-2005
Franciscan Children's Home Health	30 Warren St., Brighton, MA 02135	617-254-3800 x 5500
Interim - Hyannis	310 Barnstable Rd., Ste. 202, Hyannis, MA 02601	508-771-4117
Interim - Rockland	200 Ledgewood Place, Suite 101, Rockland, MA 02370	781-261-9616
Interim - Worcester	65 James St., Ste 201, Worcester, MA 01603	508-792-5900
Loving Care - Springfield	2095 Roosevelt Ave., Springfield, MA 01104	413-731-3050
MultiCultural/Deb Davignon	96 Industry Avenue., Ste. 1, Springfield, MA 01104	413-782-7745
New England Home Health Services	594 Marrett Road., Lexington, MA 02421	781-674-9100
Northeast Clinical Services, Inc.	89 Newbury St., Suite 202, Danvers, Ma. 01923	978-646-5200
PSA - Brockton	20 Minuteman Way, Ste. 2, Brockton, MA 02301	800-486-9870
PSA - Shrewsbury	415 Boston Trnpk Rd, Ste. 211, Shrewsbury, MA 01545	508-842-5809
Seraphic Springs - Salem	121 Loring Ave Suite 810, Salem, MA 01970	978-745-5604
Seraphic Springs - Cambridge	2464 Mass Ave Suite 315A Cambridge, MA 02140	617-547-0685
Seraphic Springs - Milford	89 Main Street, Milford, MA 01757	508-634-2401
Shrivers Nursing - Family Lives	200 Friberg Parkway Ste 2003 Westboro, MA 01581	508-475-0493

---

<b>PDN Home Health Agency</b>	<b>Address</b>	<b>Phone</b>
VNA - Cape Cod	255 Independence Drive, Hyannis, Ma 02601	508-394-2230
VNA - Salem - Partners Home Care	800 Cummings Center Ste # 166S, Beverly, MA 01915	978-236-1300
VNA - South Shore	100 Bay State Dr., Braintree, MA 02184	781-849-1717
VNA Care Network	333 Turnpike road, Southboro, MA 01772	508-786-0693

## List of Personal Care Attendant Agencies

In case you are not able to find nurses to fill your approved nursing hours, you may find a personal care attendant to be of great help. This list provides agencies that can help you begin the process.

PCA Agency	Fiscal Intermediary
<b>Ad Lib, Inc.</b> 215 North St., Pittsfield MA 01201 413-442-7047	Stavros
<b>Boston Center for Independent Living (BCIL)</b> 95 Berkeley St., Suite 206, Boston MA 02116 617-338-6665	Cerebral Palsy of Mass.
<b>Bristol Elder Services</b> 182 North Main St., Fall River MA 02720 508-675-2101	Cerebral Palsy of Mass.
<b>Center for Living and Working</b> 484 Main St., Worcester MA 01608 508-798-0350	Stavros
<b>Coastline Elderly Services</b> 1646 Purchase St., New Bedford MA 02740 508-999-6400	Cerebral Palsy of Mass.
<b>Elder Services of Berkshire County</b> 66 Wendell Ave., Pittsfield MA 01201 413-236-1718	Cerebral Palsy of Mass.
<b>Elder Services of the Merrimack Valley</b> 360 Merrimack Street Lawrence, MA 01843 978-683-7747	North Shore ARC
<b>Family Service Association of Greater Fall River</b> 151 Rock St. Fall River MA 02720 508-678-7542	Cerebral Palsy of Mass
<b>Franklin County Home Health Care Corporation (FCHCC)</b> 330 Montague City Road Turners Falls MA 01376 413-773-5555	Cerebral Palsy of Mass.
<b>Greater Lynn Senior Services (GLSS)</b> 8 Silsbee St., Lynn MA 01901 781-599-0110	North Shore ARC
<b>Greater Springfield Senior Services</b> 66 Industry Ave., Springfield MA 01104 413-781-8800	North Shore ARC

PCA Agency	Fiscal Intermediary
<b>Independence Associates, Inc.</b> 10 Oak St. 2nd floor Taunton MA 02780 508-880-5325	Stavros
<b>Montachusett Home Care Corp.</b> 680 Mechanic St. Leominster MA 01453 978-537-7411	Cerebral Palsy of Mass.
<b>Mystic Valley Elder Services</b> 300 Commercial Street Malden, MA 02148 781-324-7708	North Shore ARC
<b>Northeast Independent Living Center, Inc. (NILP)</b> 20 Ballard Rd. Lawrence MA 01843 978-687-4288	Stavros
<b>North Shore ARC</b> 6 Southside Rd. Danvers MA 01923 978-762-0301	North Shore ARC
<b>Old Colony Elderly Services</b> 144 Main St. PO Box 4469 Brockton MA 02303 508-584-1561	Cerebral Palsy of Mass.
<b>Options PCA Agency</b> 30 Taunton Green, Unit 8 Taunton MA 02780 508-880-7577	Cerebral Palsy of Mass.
<b>PRIDE</b> 3 Maple St. Taunton MA 02780 508-823-7134	North Shore ARC
<b>Somerville Cambridge Elder Services</b> 61 Medford Street Somerville, MA 02143 617-628-2601	North Shore ARC
<b>South Shore ARC</b> 371 River St. N Weymouth MA 02191 781-335-3023	Cerebral Palsy of Mass.
<b>Southwest Boston (Ethos)</b> 555 Amory St. Boston MA 02130 617-522-6700	Cerebral Palsy of Mass.

PCA Agency	Fiscal Intermediary
<b>Stavros Center for Independent Living</b> 691 S East St. Amherst MA 01002 413-256-0473	Stavros
<b>Toward Independent Living and Learning (TILL)</b> 20 Eastbrook Rd. Suite 201 Dedham MA 02026 781-329-6150	Cerebral Palsy of Mass.
<b>Tri-Valley Elder Services</b> 251 Main St. Webster MA 01570 508-949-6640	Cerebral Palsy of Mass.
<b>United Cerebral Palsy Assoc. of Metro Boston</b> 71 Arsenal St. Watertown MA 02172 617-926-5480	Cerebral Palsy of Mass.
<b>West Mass Elder Care</b> 4 Valley Mill Rd. Holyoke MA 01040 413-538-9020	Cerebral Palsy of Mass.

---

## Welcome To Holland

by Emily Perl Kingsley

© 1987 by Emily Perl Kingsley. All rights reserved

I am often asked to describe the experience of raising a child with a disability — to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this....

When you're going to have a baby, it's like planning a fabulous vacation trip — to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around ... and you begin to notice that Holland has windmills ... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away ... because the loss of that dream is a very very significant loss.

But ... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

---

## Celebrating Holland – I’m Home

by Cathy Anthony

(my follow-up to the original “Welcome to Holland” by Emily Perl Kingsley)

I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I’d planned.

I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger — the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travelers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn’t so bad.

I think that Holland is used to wayward travelers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land. Over the years, I’ve wondered what life would have been like if I’d landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest.

And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has become an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its tulips, windmills and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveler and discovered that it doesn’t matter where you land. What’s more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that Holland, or any land, has to offer.

Yes, over a decade ago, I landed in a place I hadn’t planned. Yet I am thankful, for this destination has been richer than I could have imagined!

### Complications of a Medically Complicated Child

There is a phenomenon in psychology that states that active observers—people who are involved in an action—have a great need to predict and control a situation. This couldn't hold more true for me, the mother of a child who is "medically complicated." My 20-month-old son is the actor, and I am the active observer. My son doesn't realize how unusual his life is, but I know that running from a meeting to a hospital appointment one or more times each week is not usual for many parents. I yearn to control this chaotic frenzy, but until Sam's health problems are under control, our lives will not be, either.

"Is life always like this?" our social worker asked us. She had been assigned to us by the state because our son is receiving physical and occupational therapies as part of the early intervention program. Having a social worker is perceived to be "a good thing," but it is one more appointment I need to arrange in an already crowded schedule. She also suggested we attend a support group for parents of medically complicated children. While a support group may be helpful, I don't really feel that I have the time to attend.

It is assumed that our son Sam has a connective tissue disorder. My husband and I had always thought that there was something not quite right about Sam: He cried a lot during his early months; he made no attempt to move or roll over; and he seemed weak. His thyroid screen was positive, but upon repeating it, it showed normal results. He was born with two large hematomas on his head, but the x-rays indicated that there were no abnormalities present. Sam developed a case of thrush that lasted for 5 months. After a normal immunologic evaluation, it finally cleared up without intervention. When he was 6 months old, I discovered he had several pubic hairs, but the endocrine tests that followed also showed normal results. We tried to laugh and say, "There is always something going on with Sam."

When Sam was 9 months old, we became very concerned with how his feet turned up and toward the ankle, and how his legs turned out in a bowlegged appearance. He was also developmentally delayed. At a well-visit, our pediatrician also noticed these problems. We were referred to an orthopedic surgeon, who assumed the problem was due to unusual positioning in utero, and referred Sam to physical therapy. Physical therapy helped a little, but it became clear that a 2-month fix was not going to help our son in the long term.

Later, our pediatrician caught a glimpse of Sam's left eye turning outward. Assuming this was strabismus, she referred us to a pediatric ophthalmologist for further examination. It was on 16 July 2002 that we found out that Sam had bilateral ectopia lentis. Sam's lenses in both eyes were not located behind the pupil and iris as they should have been, but were displaced outward and upward. As a

result, Sam was focusing through the curved part of the lenses, and he was highly myopic. One reason that Sam had not wanted to move very much became clear: He couldn't see beyond what was literally in front of his face. While this information was disturbing enough, we learned that dislocated lenses were often associated with genetic syndromes, such as the Marfan syndrome, homocystinuria, and the Weill–Marchesani syndrome. The latter two were unfamiliar to me, but I knew a woman whose brother had died of the Marfan syndrome, and that was all I could focus on for several days.

Such began the life of being a parent of a medically complicated child. We learned that we needed to become our son's biggest advocate in a confusing health care system. We learned all we could about dislocated lenses and associated syndromes through the Internet, through colleagues, and through our pediatrician, who, in this HMO world, gave more of her time to us than is imaginable. When we saw a vitreoretinologist who wanted to remove Sam's lenses, and we instinctively felt that this was not right, we contacted the National Institutes of Health and Johns Hopkins University and learned that if Sam did have the Marfan syndrome, removing the lenses was not the proper intervention. We immediately canceled the surgery, and we then found a leading pediatric ophthalmologist who specialized in genetic conditions. Our pediatrician readily agreed to refer us to this specialist; we were fit into his busy schedule within a week, and we learned that the first strategy to follow was providing Sam with corrective lenses. Days after this first visit, Sam received his glasses. He wasn't happy about wearing them at first, but within minutes, he looked around and said "Ooohhh." He was 12 months old, and he was seeing the world clearly for the first time.

We recently moved to a large, urban area, and this has corresponded to excellent medical care. Sam's diagnosis is not yet defined: He does have something, although no one knows what. Still, it is difficult for most of the physicians we see to realize the full spectrum of what we are dealing with. They view Sam through the lens of their own specialty: For example, two orthopedic surgeons think Sam has the Stickler syndrome; the otolaryngologist does not. The cardiologist and ophthalmologist think he has the Marfan syndrome. The physiatrist and neurologist think that he is doing well; the geneticist is concerned. Sam recently developed several inguinal hernias, thought to be common in people with connective tissue disorders. But Sam does not fit any one pattern clearly. Gene testing can be performed, but at \$2800 per test, the geneticists are under pressure from the health insurance company to do this only when there is clear clinical evidence that a particular syndrome may be indicated. After nearly 6 months of weekly visits to specialists, we have now been given permis-

sion for karyotyping. In May 2003, Sam was tested for the Marfan syndrome. Soon, we may know more, or no more.

Apart from a diagnosis, we need Sam to receive treatment to improve his functional status. As a psychologist, I can also see how important it is for Sam to achieve. I watch him make every effort to bend down and reach a fallen object; I can follow his eyes and see him planning his strategy to get across a room without letting go of a chair, a wall, or a table. Physicians X and Y both recommended that Sam start using corrective cable braces to turn his legs inward; however, Physician X stated that he should start using them once he starts to walk, as the cable braces will slow down his progress in walking; Physician Y stated that Sam should start using the cable braces now, and that it is more important for Sam to correct his muscle problems before he begins to walk. Who is right? Interpreting medical advice is among the challenges we face in parenting a medically complicated child.

An integrated health care system in which physicians of various specialties meet to discuss difficult cases may be one way in which medically complicated children can be best served. When Sam was diagnosed with ectopia lentis, the natural next step was for him to have an echocardiogram, given the association between dislocated lenses and the Marfan syndrome. At this appointment, we asked the cardiologist if Sam's difficulties with breathing and excessive sweating could be related to a heart problem. He dismissed this, told us that Sam's aortic root was large but not abnormally so and that no cardiac problems existed. Six months later, in our new city, Sam had a follow-up echocardiogram to recheck the aortic root size. It was then that a patent ductus arteriosus was diagnosed: This congenital heart defect may be responsible for his grunted breathing, excessive sweating, and poor weight gain. The difficulty in diagnosing this may have been due to fragmented health care. At the time of the second echocardiogram, Sam had seen many more specialty physicians, and perhaps having more input from other physicians led to a more thorough

exam in the latter case, which resulted in the detection of the patent ductus arteriosus.

Physicians struggle to determine Sam's diagnosis; therapists struggle to get Sam to reach for that ball, to turn those knees in, to take an unaided step; but we, as parents of a medically complicated child, struggle with much more. I coordinate Sam's medical records so that every physician knows what every other physician is thinking. Most physicians seem grateful for this. I try to arrange multiple procedures with multiple surgeons on the same day so that Sam will undergo anesthesia as little as possible. Many surgeons seem to want this to happen, but their scheduling staff is not always as accommodating. I consult with our daycare center to determine how Sam can best be served next year in a classroom where everyone is walking but he may not be. I meet with our daughter's teachers to discuss her behavioral problems, possible signs of the stress she feels. I struggle with keeping up with my work when I need to take off so much time to attend medical appointments. While I know that Sam is not any physician's only patient, I wish sometimes that they and the office staff would attempt to act like it. Recently, a pediatric surgeon asked me how I was coping with all of Sam's complications. It was the first time any physician had asked me how I felt. I wish it happened more often. But more important, I wish that physicians had a better system in which they could ask their colleagues of other specialties how *they* felt about a medically complicated child.

*Rani Ghose, PhD*  
Bedford, MA 01730

**Note:** Names have been changed to protect the identities of the patient and the treating physicians.

**Requests for Single Reprints:** Rani Ghose, PhD; e-mail, rani\_ghose@hotmail.com.

*Ann Intern Med.* 2003;139:301-302.