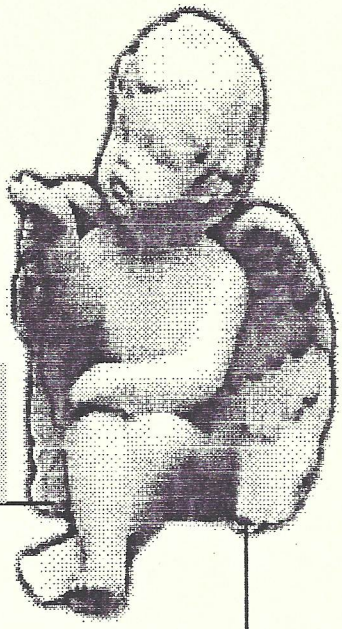


SPRING 1996

CHERUBS

The
Association
of
Congenital
Diaphragmatic
Hernia
Research,
Advocacy,
and
Support

Since our last newsletter, our membership is slowly growing. We have joined many other support groups to help families like us. Unfortunately our donations have not grown. We still do not charge families membership fees, and I hope we never do. You've probably heard the term; "shoe-string budget". Well, our budget is a shoe-string that is unraveling. We thank the doctors and other medical professionals who have donated money over the past year and it certainly has helped us to pay postage, printing, and office supply costs. I never wanted CHERUBS to be the type of organization to "beg" for money from the public, and I hope it won't come to that. I want to keep CHERUBS going, but I need your help. Below you will find our "wish list" for equipment and supplies that we desperately need. If you have any ideas about how we can obtain these objects, or any fundraising ideas, please let me know. All donations are tax-deductible. We are also in the process of starting a Food Lion supported fundraiser (more information about this is on page 4). It is hard to have fund-raisers, since we all live so far apart.

Many of you had questions about the survey. It might be helpful to use the Parent Reference Guide "Medical Terms You Need To Know". A lot of you don't know what type of CDH your child has. Look through the medical terms, and if you still aren't sure, ask your child's doctor. There are a lot of surveys out there that haven't been returned. If it means you have to take longer to find out all the information, please take your time. We need the surveys to be as exact as possible. It took me two days to go over my son's survey and find all the information needed; so if you don't know all the answers off of the top of your head, you're not alone.

Exceptional Parent Magazine has been kind enough to send me several copies of a recent issue of their magazine for our members. If any of you would like a free issue of this wonderful magazine for parents of disabled children, please send $3.00 to cover postage costs. We still need stories and pictures for future newsletters. If all goes well, CHERUBS will be represented at the 1996 convention of American Pediatric Surgeons, we need pictures of our cherubs to take with us this May. I hope all of the parent matches that we have found for you have helped. If any of you find that your matches just are not quite what you need, please let me know.

CHERUBS Would Like to Thank The Following People for Their Help and Support:

American Pediatric Surgical Association
Exceptional Parent Magazine
Karen Greendale, MD- GENESIS
John A. Harris, MD, MPH- Chief
California Birth Defects Monitoring Program
Jeff Jenkins, Director of Marketing
Alpha-Omega Health, Inc.
Jacob C. Langer, MD, FRCS(C)-
Associate Professor of Surgery and Pediatrics
St. Louis Children's Hospital,
Washington University in St. Louis
Lesli A. Taylor, MD- Assistant Professor of Pediatric Surgery
University of North Carolina at Chapel Hill
Claudine P. Torfs, PhD- Epidemiologist
California Birth Defects Monitoring Program
Jay Mark Wilson, MD- Associate in Surgery,
Boston Children's Hospital
Harvard Medical School
Gayle Willson, ECMO Moms and Dads International
Parent Support
Robert Wood, MD- Pediatric Pulmonology
University of North Carolina at Chapel Hill

CHERUBS Would Like to Thank The Following People for Their Generous Contributions:

Alpha-Omega Health, Inc.
Joe and Linda Horton
Rachel King, RN
Duke University Pediatric Intensive Care Unit
North Carolina Assistive Technology Program
Cassandra Stoddart, Executive Director
Circuit City Foundation
University of North Carolina at Chapel Hill,
Holiday Card Project Fund
Jay Mark Wilson, MD- Associate in Surgery,
Boston Children's Hospital
Harvard Medical School

CHERUBS WISH LIST

* A computer system (any brand) and accesories, including:
  * 8 or 16 MB memory
  * 1.2 or 1 gigabyte hard drive
  * quad-speed CD-ROM drive
  * 3.5" disk drive
  * a 14" .28 dot pitch color monitor
  * keyboard and mouse
  * 1 MB video memory
  * a telephone answering system
  * a 14.4 internal fax/modem, capable of creating graphics
  * full-duplex speakerphone
  * a color, laser jet printer
  * a computer scanner (so we can include clear pictures)
  * computer software, including: MS Windows '95, MS Encarta '96, America Online, Compuserve, Clip Art (especially that which include angels and cherubs), Microsoft Word, Desktop Publishing, MS Money, Lotus, and Spreadsheet software.
* A copy machine capable of dual-sided copying on 17" x 28" paper
* A four-drawer, fire-proof, filing cabinet
* Envelopes, any size
* 9 and a half inch x 11" Computer paper
* Stamps
* 17" x 28" paper in various colors for newsletters
* Files
* Ink pads
* Cards; birthday, sympathy, congratulations on the new addition

CHERUBS is an international organization for families and care-givers of children and adults who are diagnosed with Congenital Diaphragmatic Hernias (CDH). CHERUBS provides information, support, and parent-to-parent matches. There is no cost to parents for services provided by CHERUBS. We are a volunteer organization founded in February of 1995 and an Internal Revenue Service recognized Non-Profit Association. Donations are very welcomed and are tax-deductible. Checks can be made out to CHERUBS. The opinions shared in this newsletter do not necessarily represent the views and opinions of all members or staff. The information in this newsletter is by no means to be substituted for proper medical advice. Remember, every child is different. You can compare the progress of another CDH child to the progress of your own child. They are all little angels.....CHERUBS.

LETTERS TO CHERUBS

January 4, 1995

Dear Ms. Torrence,

Thank you for your letter introducing me to your organization (CHERUBS). Obviously, congenital diaphragmatic hernia is a very difficult problem which has not been completely solved. The prolonged hospitalizations and chronic difficulties that these children encounter clearly is a strain for their entire family. I congratulate you for filling a much needed void in establishing this support group for the families of these children. Enclosed please find my membership fee, order form for parent reference guides, and an additional small donation. I have also enclosed several recent reprints detailing our experience here at Boston Children's Hospital with congenital diaphragmatic hernia. Finally, I am enclosing a copy of a Boston Globe article from two years ago concerning one of my patients, Patrick Lyons, because I think you would appreciate it.

I thank you once again and please let me know if I can offer any additional assistance with this very important undertaking. Best wishes.

Sincerely,
Jay M. Wilson, MD
Associate in Surgery;
Director, ECMO Program
Boston Children's Hospital
Assistant Professor of Surgery
Harvard Medical School

January 4, 1996

Dear Dawn:

It was so good to receive your newsletter. I know the importance of support groups, and I am eager to share with you the families who have experienced ECMO due to CDH. I realize that not all children who have CDH need ECMO (praise the Lord) but there is the need to be in contact with parents who have been there.

Our outreach network extends to those, who for various reasons have experienced ECMO. Our son, is almost nine years old, was an ECMO graduate after having Persistant Fetal Circulation as a neonate. I read the articles, with tears in my eyes, of families I have had the pleasure of meeting through the mail and by telephone conversations.

I wish you the very best as your group continues to grow and reach many more parents. I talked with a CDH mom today, who will definitely benefit from your newsletter. I will also guess she will call and offer to help others, after they get their baby home. That is what it is all about.

Thank you for such a needed group. If I can ever be of help to you, please call or write.

We hope you have the very best of New Years.

Sincerely,
Gayle Willson
ECMO MOMS & DADS INTERNATIONAL PARENT SUPPORT

January 8, 1996

Dear Mrs. Torrence:

Thank you for your letter of November 27, 1995, the newsletters, and your kindest wishes from Cherubs. You are doing impressive, informative, and marvelously supportive work.

We shall try to answer some of your questions. Unfortunately, we do not follow infants beyond one year of age, and then only if they return as in-patients to a hospital in our surveillance area: it would be prohibitely difficult and expensive to do otherwise. We are one of the only registries to follow infants to one year of age; most do not go past the infant's first month. Consequently we regret we do not have data to answer your first question. (My question was; "What is the rate of CDH reherniation?")

.....To answer your fourth question, among the chromosomal anomalies and syndromes associated with CDH we know of the following: trisomy 13, trisomy 18, Brachmann-de-Lange syndrome, DiGeorge sequence, Ehlers-Danlos syndrome, iniencephaly sequence, Marfan syndrome, 9p- syndrome, and Fryns syndrome. Infants with Down syndrome are more likely to have the Morgagni type of defect. McKusick (Mendelian Inheritance in Man) reviews a series of reports of familial cases, which may become more frequent, as infants have only started to survive to adulthood in the past 30 years or so. However, the defect does not seem to follow straight Mendelian inheritance. There are many isolated reports of combinations of associated defects, but they do not seem to form a particular pattern.

We thank you in advance for the results of the Congenital Diaphragmatic Hernia Research Survey you are conducting among your members over one year of age; it is a worthy and time-consuming work for which we congratulate you.

With our best wishes for a happy and productive New Year, we remain

Sincerely yours,
John Harris, MD, MPH
Claudine Torfs, Ph.D.
California Birth Defects Monitoring Program

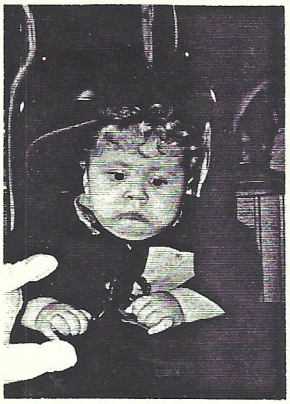
FOOD LION FUNDRAISER

This fall we plan on selling coupon books good at Food Lion grocery stores. The books will sell for $5.00 each and include coupons for $10.00 in free groceries and over $90.00 in discount coupons for major grocery products. CHERUBS will be able to keep 51% of the total sales. Food Lion will allow us to redeem this profit for cash or office equipment. They will make great Christmas presents! Please let us know if you will able to participate in this wonderful fundraiser. Our goal is to sell 10,000 books. A lot of you want to know how you can help.....this is your chance!

LETTERS FROM CHERUBS' MEMBERS

January 25, 1996

Dear Dawn,



NICHOLAS CALANDRO
born August 17, 1994

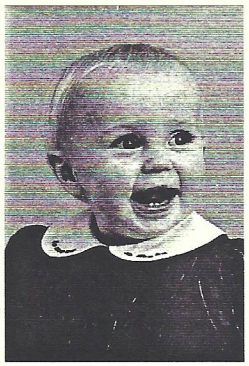
Thank you for getting in touch with me through MUMS. They're a great organization. It's been a long and lonely road, and it's nice to hear from people that have been there. I don't know how you do it! Itsounds like you have your hands full with your sweet son Shane, yet you find time to reach out to people in need. That really touches my heart! God Bless you and your family and familiies. I wanted to write to you not only to thank you but to tell a bit of Nicholas's story. I'll try to keep it brief, but he's been through a whole lifetimes worth of surgeries. Nicholas (Angel Face) Calandro was born with a pre-diagnosed diaphragmatic hernia. We found out 2 weeks prior to the C-section. Before this I had a healthy pregnancy. Of course, he was intubated immediately. Although the ECMO machines ran next to his bed for three days, we never did have to use them. Thank God! But thank God they're available for those who need them! The hernia repair was done on his 3rd day of life. All supposedly went well. Little did we know that he was going to develop adhesions on his bowel from that surgery. At just three months old he was labeled "Failure to thrive". He had severe strider and excess cartilage around his airway. He then developed a double incarcerated hernia. When the surgeon went to repair this he saw peritonitis and ended up doing exploratory surgery. That's when they found the adhesions and twisted dead bowel. The surgeon ended up removeing 85% of upper bowel (Short Bowel Syndrome). He now gets his main nutrition through a central broviac line with TPN feedings & continuous G-tube feeds to stimulate the bowel to grow.

Since Nicholas had multiple medical problems, they did some chromosome testing. His results showed that he has an unbalanced translocation of 11 and 22 chromosome, called "partial trisomy 22". Further testing on me (the mother) shows that I have a balanced translocation. My chances of having another child with this syndrome is about 33.3%. In my research of this chromosome abnormality I found that a diaphragmatic hernia is fairly common. Some of Nicholas's birth defects include; Partial Trisomy 22 (this explains all of the following defects, diaphragmatic hernia (repaired), post cleft palate (repaired), Ileostomy (repaired), Severe Laryngomalacia, Reactive Airway Disease, Grade III Vesicoureteral reflux with Proten Urial & Hamaturia, Metabolic Bone Disease, Short Bowel Syndrom Central Hyperalimentation, Seizure Disorder (no seizures since last year), had a subdual drain, Hypocomplementemia causing Nephritis, Subglottic Stenosis, Gastroesophageal Reflux, had a cricoid split, Criyptosporidium Gastitus, Recurrent otitis Media, Recurrent fevers, Large Ventricles, Abnormal EEG, Developmentally delayed, and Double incarcerated hernia (one side repaired). Nicholas is 17 months old. He's come along way medically. We still have a long way to go. At least another year on the TPN IV feedings. But because of his chromosome abnormality as well as his 18 surgeries, he is quite developmentally delayed. He is just learning to sit up, but mostly needs to be supported. He doesn't like to day on his tummy and doesn't use his limbs too much. The developmental part is becoming very hard to deal with. I tend to dwell to much on what it's going to be like down the road. Nicholas is doing very well. Maybe it's because of all the cherubs I have through out the house! My home nurses call him "The little Cherub" with his blonde curley hair and his chubby cheeks and body! Call if you'd like and keep up the great work! I know what you're doing with your organization is helping people immensely! It did me! Writing this letter has been great therapy!

Thank you for all your thoughtfulness,
Julie Ann Calandro
821 Rustic Oaks Drive, Palm Harbor, FL 34684
(left-sided CDH, Partial Trisomy 22, Multiple birth defects and complications)

January, 1996

Dear Dawn,



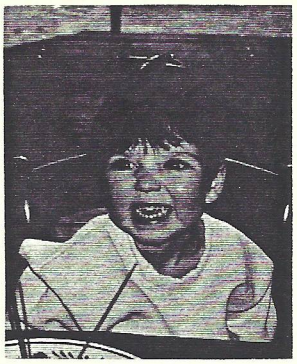
ALYSHA RHIANNON LANE
born OCTOBER 11, 1994

Hope you all had a lovely Christmas and we hope the New Year will be good for Cherubs and we are looking forward to your next newsletter. It was really encouraging last year when we received your newsletter and we have since written to several families, some have replied and some have not. I do think the 1st year is the worst and we are now more optimistic for the future with Alysha. Anyway here as promised is a brief outline of what happened to us. As you can see from this photo it was all worth it. At around 24 weeks I was sent for a scan as normal. It was on a Monday and they asked me to come back on Griday as they could not see all the baby. However the next day I saw my G.P. who said, you do know there is something wrong with your baby don't you. He then went on to explain it as best he could, and I was glad so at least when we went back to the hospital we were able to ask to be shown what the problem was. It was not until I was 37 weeks that we found and met the consultant who would take Alysha on. The hospital was 50 miles away, our local hospital just could not deal with it. I was booked in to be induced at 38 weeks. The labour and birth were normal and they went out of their way to make it as positive as possible. Alysha was born at 2.55 in the afternoon, she let out one cry as they whisked her away to be placed straight on a ventilator. We were overjoyed. It seemed like forever until they said we could go and see her, in the meantime I had been cuddling two tiny polaroid pictures. She was a reasonable weight at 6lb 7ozs. The first visit to the SCBU (special care baby unit) was so scary, seing her for the first time covered in tubes and monitors. She was heavily sedated. On the 3rd day we decided to have her christened by the hospital chaplain it was just us and a couple of nurses, it was really weird, with what should have been a family time instead it was full of strangers. We had told all our family and friends about Alysha before he birth. so many people refrained from sending us cards because she was so ill. We found that really odd too because what happened in the next few hours, days or weeks. After 1 week she was said to be stable enough to go ahead with the operation. So I had my first hold for about 3 minutes, still attached to the ventilator and other drips and monitors. We didn't get to hold her again for another 7 days. The op. went really well and her diaphragm was repaired using gortex. I honestly think that was the longest morning of our lives, wondering whether she would come back from theatre alive. She was ventilated for 2 more weeks after which she was able to breath on her own. At last we could pick her up properly. After 1 more week they said she could be transferred to our local hospital which was a big relief as we were traveling 100 miles every 2 days to see her. It was then only another week before they allowed her home. We tube fed Alysha for 9 and half months and she has had quite a few chest infections and we nebulise her four times a day more if she's poorly. But her smile and determination makes it more worthwhile, development is normal for her age although she will always be small she will not win the school reace, but to us she is just Alysha and she is special to us, so if your child has recently been diagnosed do not give up, it is a long uphill struggle at times, but it is worth it.

love,
Brenda, Kevin, Harrison, and Alysha Lane
43 Vancouver Ave, King's Lynn, Norfolk, PE30 5RD, England
(left-sided CDH, Hemivertebrae T3, Asthma)

January, 1996

Dear Dawn,



ANNA TIJAN
born April 6, 1992

It is now the month of January, another new year, a chance to look back and see just how far we've come. After a normal pregnancy, an induced labor (our doctor feared a home birth), and with no warning or hint of trouble, Anna came into this world with a very hard road ahead. Anna was born in a northwoods hospital where we were the only ones on the floor. It was suppose to be such a normal labor and delivery that the pediatrician on call had rode his bike home. Little did he know that enroute to his home, he was desperately being called back for a baby in distress- our Anna. She had turned deep purple immediately after the cord was cut. While waiting for the pediatrician to get back to the hospital, a team of nurses worked hard along with my OB to keep Anna alive. After a quick trip to x-ray the doctor came in to tell us the news, a diaphragmatic hernia was threatening our baby's life. A large hospital some 150 miles away was called to take her. They declined saying she was too critical. A Minnesota hospital was called and a transport team along with flight for life was on their way to pick up our daugher. Once they arrived back in Minnesota they called to get permission to put her on ECMO, for with ECMO she stood a 10% chance. without it far less. She stayed on ECMO 20 days until she was stable enough for surgery. While they were in repairing the hernia, they did a Nissen. The Nissen did not hold so a second one was performed along with a G-tube. During her six month stay, Anna had 10 surgeries; two of them being shunts due to water on the brain. She remained on the vent for 5 months with 2 failed attempts. She came home when she was 6 months old with staples in her head from a shunt repair just 4 days earlier. She came home with oxygen and remained on it for 11 more months. I must tell you- against the hospitals suggestions, we refused nursing help at home. My husband and I felt that we were the best for Anna and in our case, we were right. it was hard and very draining but we wouldn't have it any other way. The hospital also wanted her to have both OT and PT daily. Switching off and on which turned out to be too much. She developed congested heart failure and spent a week in a nearby hospital. We again stepped in and said no more PT and only once a week OT which proved to be the right choice. We daily took her blood pressure and did her vitals, keeping a daily diary of our steps forward. We continued to feed her through her G-tube with Pediasure up until her 3rd year when she finally started to eat. At the age of 3 and a half years, we still feed her 1 - 2 cans through her tube at night leaving the day to oral feedings. At our hospital and clinic some 150 miles away, she has had a number of doctors (eight or so) all in their own fields - all telling us we surely have a miracle baby, that she is enjoying life as a normal 3 yr old (except for that tube sticking out of her tummy). We have so much to be thankful for - God has blessed us with a miracle at a point in our life when we thought we were all through having children (a 10 year age difference), at an age when we can emotionally handle th heartaches of a critical baby.

Dawn, we thank you so very much for Cherubs, for the connection or closeness we feel for the other families in the newsletters. We all share a bond having CDH babies touch our lives. I look forward to the results of the survery - anxious to see what we as parents have in common.

We wish you all a happy and healthier New Year,

Joan Tijan
Rt 2 Box 986, Crandon, WI 54520
(left-sided CDH, ECMO, G-tube, Hydrocephalus, BPD, other complications)

A letter written from one of our members to her parent matches (January, 1996)::

Last fall I was given your name and address by Dawn Torrence of Cherubs, as parent matches. For many reasons, I have not had the time to contact you until now -- it's on the top of my New Years Resolution List of "things to do"!

Frankly, when I first received Dawn's informative newsletter I was stunned and sickened; it stirred many memories for me that I had long since buried in the gray matter of my mind. It was disturbing to relive the nightmare -- and to realize that others were enduring the same hell.

I am the mother of a young man who will be 21 years old in April. Brian was born with right-sided diaphragmatic hernia and bilateral phrenic nerve agenesis. While the hernia was repaired on the day he was born, the lack of functioning phrenic nerves left him with no functioning diaphragm He was subsequently hospitalized in the NICU for two years. We brought him home with oxygen, G-tube, ventilator, tracheostomy, etc., etc., etc. Getting the hospital staff to release him was a major battle; remember, this was almost 20 years ago -- before home health care was universally accepted.

It would be impossible for me to share every detail without writing a book (and someday I might just do that). I would like to share some highlights that, in hind-sight, I feel are major considerations:

1. Get your child out of the hospital and into your home as early as possible. Get involved in the care while he/she is still in the hospital. Learn, ask questions, demonstrate hands-on involvement!! Prove that you are concerned and qualified to care for your child at home!

2. Speak up -- speak out!! Your child cannot speak or defend himself/herself -- you must be their voice! Don't be intimidated! Be assertive, but speak calmly and clearly, always with a "please" and "thank you".

3. Begin feedings by mouth as early as possible. To this day, Brian will consume nothing but water by mouth, and receives nutrition via G-tube. He remains very oral sensitive, and anything with flavor or texture he finds offensive and will gag vigorously. We have tried everything imaginable to encourage oral feedings through the years -- all in vain!! I have come to the conclusion that it is a behavioral thing -- he finds it time consuming to sit and eat; it is much less work to hook himself up to a feeding pump at night before he goes to bed. Because he as never developed those facial muscles for mastication, his oral cavity is malocclueded with flaccid nusculature, resulting in numerous periodontal surgeries, orthodontic work, years of speech of speech therapy, and continued "lazy" speech patterns because of the untonrd tongue, lips, and cheek muscles. Be aware that while liquid tube feedings may be nutritionally "complete" in content, they may have side effects when used solely and over a long peroid of time. At age 5 Brian developed syptoms related to gallbladder disease. Further tests revealed gallstones, a result if his diet. He had his gallbladder removed, and because of complications resulting from failure to recognize the musculature involved in his breathing process per the DH repair, when the sutures were removed one Thanksgiving morning, his entire incision opened, pouring his abdominal contents into his lap, returning him to the OR and subsequent ICU stay-- an absolute nightmare!!

4. Get your child involved in activities with other children as early as possible. Brian was in a pre-school program at age 3, and then on to regular public school kindergarten, grade school, etc. While children can be brutally honest, and often cruel, through instruction and education, acceptance will result.

5. Consider the need for supplemental oxygen during periods of sleep and exercise. Through a sas series of errors between physicians, this information was never relayed to us and as a result, Brian has developed pulmonary hypertension, a serious, life-threatening complication of hypoxia. He is now maintained on oxygen 24 hours a day and must use a rocking bed or BiPAP machine for non-invasive ventilator assistance. He was not able to attend middle school and most of high school, but his senior year was stable enough to attend classes and walk across the stage (as a member of the National Honor Society) on graduation day to receive his diploma -- his goal!!

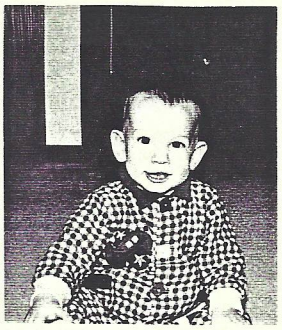
Today Brian is in his second year at our local university, driving to school each day, throwing his oxygen unit in his back-pack. In the first months of his life, physicians encouraged us to "pull the plug", saying he was blind, deaf, and probably severly retarded -- if they could see him now!! His battle is certainly far from over. Each day is a gift and I feel he lives a happy life. It provides some solace to me to realize that Brian has never known any life different from the one he lives each day. Every breath is an effort, but that is the way it has always been for him, so he doesn't know what "normal" really is -- so his struggle to survive is "normal" to him. I would be happy to share any thoughts or ideas with you and hope you will feel comfortable contacting me. I have learned to take one day at a time; we have good days and better days. You must take care of yourselves as parents -- you are the caregivers. Stay well and strong! I hope to hear from you soon!

Warmly,

Debbie Decker
1839 Westward Drive, Wadsworth, Ohio 44281-8504
(mother of Brian Decker, born April 6, 1975)

January, 1996

Dear Dawn,



Luke Nowakowski
born March 12, 1995

Thank you so much for the Cherubs newsletters. Reading them brings us a lot of hope for the future. I had a normal, healthy pregnancy. I had three ultrasounds; 10 weeks, 20 weeks, and 42 weeks. There were no indications that there was a problem and not once during my pregnancy did I even think about having an unhealthy baby.

Ten months ago on March 12, 1995, our first baby was born. Luke came out in respiratory distress. The Ob/Gyn told the nurse to get the pediatrician. Within seconds, he and about six nurses came running into the room. By that time, the anestesiologist was "bagging" him. After several minutes he started to breath and the pediatrician said he needed a chest x-ray. We found out much later that they had to put him on life support before they even took the x-ray. The pediatrician said Luke had gone limp in his arms and didn't think he would make it. Twenty minutes later he told us that Luke had a CDH and that he needed surgery and would need to be transferred to another hospital forty minutes away. I had only seen Luke for about ten seconds after he was born and then again four hours when the transport team brought him to my room in an isolet. They opened the door and I was able to touch his arm. I hadn't even noticed the tubes and wires that surrounded him. The doctor said that they needed to go and that "you have a very sick little boy". I still had no idea how serious this was, I guess I was in shock. I thought he would have surgery and would be home in a week. My husband went with Luke and my mom stayed with me. When I got home the next night, it hit me - "why isn't our baby with us? This isn't the way it was supposed to happen!" All I could do was cry and ask why. My stomach had a constant knot in it and I swear i could feel my heart breaking.

Thirty four hours after Luke was born they did the surgery. The doctors had thought both lungs were fully developed but after surgery, the doctor said the left side was only 20% the size it should be and the right side was a little smaller than normal because his heart was pushed over. They told us that fortunately only his intestines had gone into his chest. The surgeon said that the hole in his diaphragm was so large that he had to use a gortex patch to permanently repair it. He also told us that he could not fit the intestine where they belonged so he had to make a ventral hernia. This will repaired when Luke is about one year old. It will be his fourth and hopefully final surgery (original CDH repair, 2 for ECMO). After Luke's surgery was when we had learned about ECMO. We kept praying that he wouldn't need it because the way the doctors talked to us about all the possible complications from it, made it sound like a definate death sentence. When we left the hospital that night, Luke was doing well. Around 11:00 that evening the surgeon called us just to let us know he was doing great and that he didn't think ECMO would be needed. At 3:40 am the hospital called and said he wasn't doing well and that they needed our permission to put him ECMO. We hung up the phone and started to cry and pray. Even now, the memory of this is so painful. When we arrived at the hospital, they had just finished surgery and told us if we didn't give our permission to go on ECMO that Luke would have alrealy been dead. Thankfully, he was only on it for 3 days which was the minmum they said he would need. Seven days later he came off the ventilator and I was able to hold our baby. I thought it would be this really emotional time it wasn't. I was too worried about pulling out his chest tube or his NG-tube, etc.. I felt guilty and thought that there must be something wrong with me. I kept thinking "don't you love this baby? Why aren't you crying? After all, it's been twelve days since he was born and you're finally holding him!" I know now that it was ok to feel that way and that there wasn't anything wrong with me. The next day my husband held him for an hour. He didn't want to let him go. He felt bad because for the first several days of Luke's life he couldn't be held and he wanted him to know he was loved. I saw a side of my husband that I had never seen before, a different kind of gentleness and love that just seemed so natural.

When Luke was about four weeks old he no longer needed oxygen but needed a daily dose of Lasix & Theophylline to help him with his breathing. In addition to CDH and ECMO, Luke was treated for anemia, jaundice, bradycardia, thrombocytopenia, pleural effusion, gastroesophageal reflux, and small left lung. After 5 and half weeks we were finally able to bring Luke home. it seemed like forever but considering the fact that they had told us he would probably be there for three months, it was no time at all. Luke was still on the two medications for his breathing, he had an NG tube and was on Cisapride which helped his reflux. One month later he was off NG feeding and by the time he was four months old he was off all of the medications.

Developmentally, Luke is where he should be for a ten month old. Actually, he is already walking so he's a little ahead of schedule. He suffered from hyperontia due to his ventral hernia so he see's a physical therapist but is doing much better. He also see's an occupational therapist because he tends to keep his left hand clenched. The doctors don't think it's due to the permanent cutting of the internal jugular vein and coraded artery in his neck but they don't know for sure. Luke will use his left hand to pick up things but tends to keep his thumb tucked in and primarily uses his right hand. If anyone else has experienced this problem, we would love to hear from them.

Right now we are trying to get him through the winter without getting sick. We don't take him to stores and we only see people if they aren't ill. We have had many last minute cancellations because of someone getting sick. The doctors say we should be able to treat him like a "healthy" child by the summer time. We can't imagine letting people touch him without washing their hands first. We don't think we will ever be ready for that. When the time comes, we'll all be waiting for about four days holding our breath to see if he caught anything. We wonder if we'll ever be able to forget about the pain we've gone through and really be able to treat Luke like a "healthy" person. We wonder if we will see him get sick and not painc.

It's God's grace that has gotten us this far so we will just have to continue trusting Him. When we get upset we turn to Psalm 139: 13-16 and it remings us that this wasn't an accident or a "freak of nature". We truly feel blessed to have Luke in our life, he has brought us more joy than we even could imagine. He makes us laugh everyday and we thank God for his precious life. We sometimes feel guilty because we get sad and still ask "why" when we know things could be so much worse. We are very fortunate that Luke is as healthy as he is and is not showing any side effects from ECMO. We often pray for the other parents and their "Cherubs" that they would be as blessed as we are and that someday they will be able to put all the bad things behind them and cherish the precious time they have together.

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Breathing life into baby Patrick

taken from The Boston Globe, December 9, 1993 issue
written by Irene Sege, Globe staff

At Patrick Lyons' first baptism, on March 18, the holy water on his brow symbolized more anticipation of death than celebration of life.

He was one day old, and his belly was flat, not newborn round, because his intestines were in his chest cavity, where his lungs should have grown, rather than in his abdomen where they would have pushed his soft baby skin into the sweet curve of normalcy.

The intestines had migrated, during gestation, through an opening in his diaphragm that should have closed but didn't, so Patrick was born with lungs so undeveloped that when he tried to take his first breath and utter the first cry of life, his mother and his father and the seven doctors and nurses in the delivery at Boston's Beth Israel Hospital heard nothing, only silence.

By the time Rev. George Gardner reached Patrick's bedside at Children's Hospital the next day, the baby lay tethered to machines of man striving to save God's work. He was sedated, immobile, so he would not disturb the blood from his jugular vein or the tube that carried blood back into his carotid artery, bright red after being oxygenated outside his body in equipment that acts as both heart and lungs.

Patrick's parents, Linda and Kent Lyons, sat in a waiting room off the intensive care unit, Linda sobbing, then quiet, and fingering rosary bends, Kent leafing through magazines but not reading.

Linda wanted her son baptized, but Father George said sacraments are best performed in the parish church, and Patrick was expected to survive that day's surgery to repair his congenital diaphragmatic hernia. So when a nurse called and told Kent that Father George had baptized his son, Linda wept again. "I thought something had to be going wrong," she says.

Today Patrick Lyons, still small for his age and feeding through a tube to his stomach and getting a boost of oxygen through nasal prongs while his lungs continue to grow, lives on the frontier of modern medicine, diagnosed prenatally, through ultrasound, and alive now because of sophisticated, and expensive, equipment not available a decade ago. So far, Patrick's medical bills - including hospitalization and home care, but excluding doctor's cost - exceed $350,000, the overwhelming bulk covered by private insurance.

Yet as advanced as Patrick's treatment is, and as rosy his prognosis - babies with this anomaly who survive a few weeks are often indistinguishable from other toddlers by the time they are 2 - the one-third mortality for diaphragmatic hernias remains higher than the mortality rate for many childhood cancers.

"This is the edge of the envelope." says Dr. Jay Wilson, the Children's Hospital surgeon overseeing Patrick's care. "There's no sicker kid that survives with any regularity than a kid with a diaphragmatic hernia. Every peice of modern technology is used to save their lives."

For Linda and Kent Lyons, these last 11 months, from the day Patrick was diagnosed in utero, have been a roller coaster of heartache and hope, of wondering how they could manage another day and then finding the answer in their baby's smile.

For Dr. Wilson, the realization that the extracorporeal membrane oxygenation, or ECMO, that saved Patrick's life is not a miracle cure after all fuels his passion for more research.

For a nation debating health care reform, the opening chapter of Patrick Lyons' life story suggests as much about such complex issues as cost containment and medical progress as it does about one baby's struggle to overcome a specific birth defect.

"Why does the system get more and more expensive?" asks medical ethicist George Annas of Boston University. "You develop things like ECMO that work and are real expensive. And it's good. ECMO is a good thing. The real question is how to prioritize new medical technologies and to put the emphasis on what can do the greatest good for the greatest number."

Linda Kotfila and Kent Lyons met in 1984, at Holyoke Community College, where they both were students. She was quiet, shy, and he was a little wild, driving souped-up cars as fast as he could and not looking for fights, but not backing down either. By the time they wed in 1989, everyone said Kent had changed so much, had calmed down. Linda was more open, less awkward.

Now Kent, who is 29, is a traveling salesman, covering New England to sell industrial equipment, and he earns about $44,000 a year, including his car allowance. Linda, who is 28, worked as a secretary, making $26,000 a year, until May 31, when she quit because of time Patrick's care would require. She studied nursing for a year and still hopes to become a nurse one day.

They were living in Taunton when Patrick was born, but planned to buy a house in Ware in August to be closer to their families.

Linda had miscarried the year before, at eight weeks, but early miscarriage are so common doctors estimate one-fifth of pregnancies end in miscarriage, usually in the first trimester. Everthing seemed fine this time, yet the miscarriage haunted Linda. She's nervous anyway, often lightly scratching her arm, back and forth, back and forth, with her long fingernails.

"I wouldn't even say I was having a baby," Linda recalls. "I'd say 'I'm pregnant.' We didn't even look at furniture or anything like that because I didn't feel comfortable planning."

Her obstetrician, Dr. William Watson of Morton Hospital in Taunton, only orders ultrasound for a medical reason or if a patient asks. When she was 29 weeks pregnant, Linda requested ultrasound, for reassurance, not to consider a late abortion if her baby had a serious birth defect.

At her checkup on Jan 8, four days after what seemed a routine sonogram - she even had pictures of the fetus - Dr. Watson said the ultrasound looked suspiccious. Could she go to Women & Infants Hospital in Providence for a more detailed scan?

"I kept saying, 'Well, they made a mistake. You'll get down there and find out they made a mistake," says Kent, who grabs a chance for optimism as fast as Linda grabs a chance for worry.

On Jan. 12, Linda went to Rhode Island. When she walked into the examining room she felt faint, and the technician had her lie on her side and gave her cool cloths. She was shaking as the technician spread jelly on her skin and ran the scanner over her belly. She couldn't see the screen, and she tried, in vain, to follow the discussion between the technician and the doctor. Then the doctor gave her the news she didn't want to hear.

I got all worked up. I got a bloody nose," Linda says. "The doctor was saying it was 50-50. He explained basically how it is, that the lung was not all there. This was a lot for me to handle, so we didn't talk too much."

The story of Patrick Lyons is filled with "what ifs," unknowable "what ifs," and one of the biggest is this: What if Linda had not recieved ultrasound? Would Patrick be alive if he had been born at Morton Hospital? Could he have survived being transported to Women & Infants Hospital, the nearest tertiary care center, which does not have ECMO, then taken to Children's, which is one of 101 neonatal ECMO centers in the country?

To Linda and Kent, ultrasound saved Patrick's life. Dr. Wilson thinks it could have made a difference, because Patrick went on ECMO only five hours after birth. Still, these answers are speculative, and the mere asking raises other questions. For the past five years, the American College of Obstetrician's and Gynecologist has said it cannot recommend the routine use of ultrasound in pregnancy because research had not clearly shown the benefit of ultrasound for healthy pregnant women who, like Lyons, display no medical signs of needing to be screened.

In September, the New England Journal of Medicine published a study of more than 15,000 pregnant women, the largest randomized trial to date, that found no difference in newborn death or health problems among babies whose mothers were routinely screened during pregnancy and those mothers received ultrasound only if medically indicated. Likewise, there was no difference in abortion rates between the two groups. The issue remains controversial, and the National Institutes of Health and the obstetricians' group are examining the study's implications. There are a few congenital anomalies, diaphragmatic hernia among them, that call for immediate action after birth and where, presumably, the time for preparation afforded by prenatal detection could prove valuable. Diaphragmatic hernias occur in roughly one of every 4,000 live births. Other problems that could require quick response are also uncommon.

These cases, says Dr. Michael LeFevre of the University of Missouri, provide "a wonderful example of the dilemma we still have." Should doctors screen all pregnant women to help a very few? Putting the cost of the average scan at $200, the study's authors estimate the added cost could run into hundreds of millions of dollars.

"If you decide there are limited dollars that can go to health care, how do you decide where those dollars go?" asks LeFevre, a co-author of the recent study. "Most people would say we should be saving lives first, we should be worrying about reassurance and prepartation for birth defects later. It's not like they're all going to die if you don't know."

Linda and Kent Lyons met Dr. Wilson on a blustery day in late January, after Kent's sister, Donna Chadwick, who is a billing supervisor for a group of pediatric specialists in Atlanta, told them about ECMO and steered them to Dr. Wilson.

Dr. Wilson is 39 years old, educated at the University of Massachusetts and MIT and Albert Einstein College of Medicine in New York, boyish-looking despite his graying hair, and when he's not meeting with patients or performing surgery, he's in his laboratory, simulating diaphragmatic hernias in the fetuses of pregnant sheep and finding that applying pressure to the fetal trachea stimulates lung growth and wondering if the discovery is going to help babies in two years, or 20, or lead to a dead end..

These days, 80 percent of Dr. Wilsons's diaphragmatic hernia patients are diagnosed prenatally. A decade ago, none were. "I try and prepare them for a horrible experience. It is either going to bring families together or tear them apart," Dr. Wilson says. "I tell them this is so difficult we're going to work together as a team."

Dr. Wilson told Linda and Kent he could not predict the extent of any baby's hernia. One-third are born pink and breathing, albeit with difficulty, and need only a ventilator and surgery to repair the hernia and a frew weeks in the hospital. Another third are so sick, the carbon dioxide in their blood so high, their lungs so undeveloped, that even with ECMO 90 percent die.

Newborns in a middle third - which will be Patrick's group - need ECMO within 24 hours because the ventilaro pressure needed to provide enough oxygen to the brain is so high it threatens lungs and life. Before ECMO, 80 percent of these babies died, with ECMO, Dr. Wilson says, 80 percent survive. The first year is rocky, but after that children tend to do well. A child's lungs continue to grow for the first eight years of life.

Almost half of fetuses with diaphragmatic hernias have other problems, too, so Dr. Jack Ludmir, Linda's high risk obstetrician at Beth Israel Hospital, performed amniocentesis to check for chromosomal abnormalities. He ordered more ultrasound. If something else was wrong, then the baby would likely die.

This time the news was good, if you can call news good when you're carrying a baby who might not be growing any lungs at all. The tests showed no other problems. Ludmir then called Dr. Michael Harrison at the University of California at San Francisco, who performs prenatal surgery on fetuses with diaphragmatic hernias and no additional anomalies, surgery whose promise is limited by the risk of premature birth. Would Linda Lyons, then 32 weeks pregnant, be a candidate for the experimental surgery? Ludmir asked. No, Harrison said, it was too late for the lungs to have time to develop in utero.

At Christmas last year, Linda and Kent Lyons put a crib and bureau on layaway. They canceled the order after the ultrasound in January. Linda told her sister she didn't want a baby shower. Friends and family would hear the word "hernia" and think of relatively benign abdominal hernias. "The thing is, when you tell someone," Kent says, "they say, 'Oh, hernia. I had that when I was a baby.'" "Here I am, afraid and ready to cry, and saying, 'No, you don't understand,' " Linda says. "A guy I worked with's wife said, 'Oh, she must be having a boy,' and she named off like five people she knew who had boys who all had hernias when they were born. I didn't want them to say it will be OK. I got upset. How do you know? I don't know. The doctors don't know."

Patrick Thomas Lyons was born at 10:43 p.m. on March 17, a boy born on St. Patrick's Day, just as his father, who wore a green Larry Bird golf shirt to the delivery room, wanted. He weighed 6 pounds 10 ounces. Right away, he turned a dusky blue. Doctors ran a tube down Patrick's throat, and a neonatologist pumped oxygen into his lungs with a hand-held bag. A few hours later, when Linda and Kent saw Patrick just before he was taken across the street to Children's Hospital, the boy had so much tape on his face and body, holding tubes and monitoring patches in place, that the only space Linda could find to touch her newborn son was a patch of skin on his cheeks.

Through those last weeks of pregnancy, Linda pushed aside visions of a baby in a casket and Kent asked himself, "Where would bury him?" Yet they never talked about the possibility of death, and Linda never voiced her fears about what losing a baby would do to Kent, vulnerable his whole life to loss because his mother died of a stroke at 38

when he was only 7 months old. "It's a chip on my shoulder that I keep," says Kent, his round face the same round face as his son's. "If anything happened to Patrick, that would have been the last straw-type deal. My faith, as it is now, is borderline. I'm not one of those who puts all their fath there, that everything is done for a reason. I question it all the time."

Five hours after birth, Patrick was on ECMO to give his tiny lungs time to rest and grow. Dr. Wilson, who becomes "so invested in each child it's difficult to predict death," also offers ECMO to parents whose baby falls in the group in which only 10 percent survive on ECMO. Some physicians, he says, don't.

It's an honest opinion that these kids have such a low likelihood of survival it's unfair to put these infants and their parents through the process," Dr. Wilson says. "But you still have 10 percent of the children who will do fine. That's an ethical issue I can't live with."

Dr. Wilson worked fast putting Patrick on ECMO, performing in one hour surgery that, at a normal pace, would take up to two hours, moving quickly to hook tubes the width of a screwdriver shaft into a jugualr vein and a carotoid artery, because by the time the baby is put on ECMO he is dying. Later that day Dr. Wilson performed surgery, a simple operation, really, to repair Patrick's diaphragmatic hernia.

Patrick's bed was high, so gravity could help his blood drain into the ECMO circuit below. His blood was thinned by drugs, a treatment that, until about three years ago, caused significant hemorrhaging in the brain in as many as one of five ECMO patients. "I don't think I realized the things that could go wrong," Linda says. "When I found out they were doing ultrasounds on his brain I realized, you know, he could die. He could have any kind of handicap."

Day and night, a nurse monitored Patrick's condition and a technician watched the machinery. Within four or five days, Patrick improved, and on March 25 he was weaned from ECMO and put on a respirator for another two weeks. Babies who don't improve after a week on ECMO usually don't survive, Dr. Wilson says.

On March 26, Linda held her son for the first time. Patrick was 9 days old. He was a ventilator and intravenous medication, and Linda was afraid of disconnecting his lifelines. "It is amazing to me the amount of love one person can feel just by touching and holding another," Linda wrote in her diary. "One minute he looks so delicate and fragile, and the next so strong for being able to go through what he has. They let me hold him for about 1 and half hours. Even though my legs and arm went numb, it still wasn't long enough."

The surgeons who introduced ECMO at Children's Hospital in 1984 were looking for a better way to treat newborns with congenital diaphragmatic hernias. As it happened, the babies with other problems who came to use ECMO, too, the ones who aspirated fetal waste or suffered widespread infection, are the ones who found a miracle. ECMO only boosted overall survival for the diaphragmatic hernia patients from one-half to two-thirds. Eighty percent of the other babies, whose fully developed lungs did not work, used to die; with ECMO, 90 percent live.

ECMO, with its two-on-one monitoring around the clock, is expensive. Patrick's ECMO cost $15,120 on top of $66,300 to keep him in intensive care for a month and $21,547 in surgical bills.

Kent's sister in Atlanta, Donna Chadwick, knew from her work that Patrick's care would be expensive. So she advised Kent and Linda to put the baby on both their insurance policies at birth. Kent's policy could cover whar Linda's would not. if Linda left her job, as she did, there'd be no lapse because of Patrick's pre-existing condition. It's good, too, that Kent likes his job - his third in four years and one he'd like to keep - because absent health care reform, the limit on preexisting conditions could hurt them if Kent changes insurers.

"I see people breaking their backs trying to pay back the physician charges and the hospial charges because these people were so good to their child," Chadwick says. "I'm not really concerned," says Kent. "Whatever we have to pay, we have to pay. That's the bottom line."

Next to the the fifth-floor ICU is a waiting room where, one recent day, the television was on and talk show host Montel Williams was asking guests about sex. Across the room, one couple looked so stricken, sitting, but not touching, on a sofa that the air was burdened, palpably heavy, with their grief.

Linda and Kent used to sit in this room. It is where they met the parents of the newborn boy, also a diaphragmatic hernia patient, who sailed through treatment that would have Patrick struggling. They met the parents of a boy who died on his first birthday of failed liver transplant and the parents of girl who died of a respiratory virus. They met parents torn between a sick child in the hospital and a well child at home.

Finally Linda and Kent stopped going to the waiting room. They stopped using the elevators nearest the ICU and started standing with other parents, parents they didn't know with children whose ailment they didn't know, outside a different bank of elevators long corridors way from the intensive care. It just became too difficult to mute the joy of Patrick's triumphs, the way he thrived on a brand new type of ventilator, because someone else's child had a bad spell. It was also hard to keep their baby's setback from marring someone else's good day.

So this became a way to cope, like bringing lunch in a cooler because eating out adds up or not sleeping in the hospital except on rare occasions because of mothers they met who lived their whole lives, day and night, beside their sick child's bed.

"To see so much sadness scares you," Linda says. "We would just sit at his bedside because of all the things going on with all the other kids. I was very depressed. I remember thinking, just studying Patrick, looking at him and thinking, what if he doesn't make it? I just didn't want to hear any more bad."

On April 20, when Patrick moved from intensive care to 8 West, Linda wrote this in her diary: "This is such a big change from having someone there all the time to being in a room all by himself and just having the nurse check on him from time to time. It scares me."

It is July 20, another sunny day in a summer of sunny days spent in the hospital. Patrick is 4 months old. He has lived all but five days, May 31 to June 4, in Children's Hospital. He has had two more operations, one to tighten the juncture between his esophagus and his stomach because was regurgitating most of his food and one to correct a hernia, the common kind this time. Linda finally had her baby shower.

A visitor meeting Patrick for the first time notices the thin plastic tubes running across the baby's cheeks bringing oxygen to his nostrils, and she notices the thicker feeding tube attached to his stomach, and she notices the light attached to his big toe that measures the oxygenation of his blood. To Linda and Kent, who have seen their baby, even smaller, attached to many more tubes and many more monitors, Patrick looks like he doesn't have any tubes at all. Linda brushed her long hair aside as she vents gas from

from Patrick's gastrostomy tube, the G-tube leading to his stomach, because the surgery that controls his vomiting also thwarts his ability to burp.

"I think I can handle a lot. I'm emotional about it, but I can handle it, I just have to cry a lot abut it to release it," Linda says. "We have the hope that he'll be perfectly fine. Whatever we have to deal with now I will." Any parent who has watched a sleeping baby has seen the rise and fall of the child's chest and heard the hush of air inhaled and the hush of air exhaled. On this day, a bad day, there is nothing gentle in Patrick's respiration. Each breath is a gasp.

Diaphragmatic hernia babies work so hard to breath that everything else is a struggle. Light and sound and touch and the presence of people can throw them into a frenzy. It is so difficult to eat and breathe at the same time, to bring food down the esophagus at the same time that they bring air down the trachea, to use energy to suck on a bottle, that many babies take their food through a G-tube, not by mouth.

"It's hard to bond with a sick baby," says Donna O'Neil, one of Patrick's nurses. "You don't know if they're going to live or die. You can't play with them."

Patrick looks enormous to his parents and his nurses, now that he weighs 11 pounds, but an average 4-month-old boy weighs 15 pounds, and Patrick needs calories, lots of calories. Not only must he make up for the extra energy he expends to breathe but he also must gain enough weight to push his growth to the scale of normal development. So his formula, which Linda calls disgusting, is thick, then thickened more with cooking oil. When Patrick went home on Memorial Day, he was off oxygen and taking some food by mouth. Then he caught pnuemonia, which scarred his precious lung tissue, and a few days back at Children's turned into months. He was on oxygen again, and it wasn't until mid-October that he would lick a tiny spoonful of mashed bananas.

This is life for a sick child, a few steps forward and a few steps backward, and if you're fortunate, as children with diaphragmatic hernias who survive their neonatal weeks are fortunate, the steps forward overtake the steps backward. "Never look at today compared to yesterday," is what Dr. Wilson says. "Look at today compared to last week."

July 20 is a bad day, when Patrick's complexion is ashen and everything makes him fussy, but a few days later, there is color in his cheeks. His breathing is soft, barely audible, and when his mother looks at him he smiles, then smiles again.

"I feel lucky to have Patrick," Linda says. "With his problem, where he's passed the critical points, I'm looking forward to the hope that he'll be a normal little kid." This "hope that he'll be a normal little kid" distinguishes Patick's story from some stroes making rounds lately, of anencephalic Baby K, born with only a brain stem, and 2-year-old Portia Davis, born with her brain in a sac outside her head, both kept alive in Washington -area hospitals at a cost, like Patrick, of hundreds of thousands of dollars. There are stories, too, of the old and dying whose lives are prolong, marginally, at great expense.

These are tales from the murky side of technology, where ethicists ponder the value of life, where ethicists ponder the value of life, where advocates who count 8 mllion children without health insurance and 250,00 newborns a year whose mothers had inadequate prenatal care wonder why money goes one place and not the other.

Patrick, however, experienced the miracle of medical technology. The questions about his future - Is he more likely than other children to need glasses or suffer some hearing loss? Does the surgery to his carotid artery needed to place him on ECMO increase his risk of having a stroke in 50 or 60 years? - pale beside the life made possible because he was at the time and place to survive an otherwise lethal birth defect.

In the debate over health care reform, patients like Patrick present complex issues that go beyond concern about wasteful paperwork and the misuse of technology and the concentration of resources like ECMO. Is there a cutoff under which success is so unlikely that costly treatment should not even be tried? Is that cutoff 10 percent, as with the sickest babies with diaphragmatic hernia? Less than 1 percent, as with the Siamese twins seperated earler this year in Philadelphia? Somewhere in between? "We don't know how to make these decisions," says Annas, the BU ethicist. "The guidance can't be [that] the parents want it." Will the research climate that produced today's ECMO exist to produce tomorrow's as yet unknown and potentially expensive break-through? "I don't see how you're going to be steered to things like ECMO if the incentives move more to primary care than specialty care," says ethicist Arthur Caplan of the University of Minnesolta, who has advised the White House on health care reform and supports this shift in priorities. "That's the dirty little secret of my side of the argument."

The other "little secret" is taht research also leads to less expensive, less invasive intervention, good for patient and pocketbook alike. Advances in fighting polio yielded a vaccine, not a better iron lung. Magnetic resonance imaging, or MRI, used appropriately, saves the cost and trauma of exploratory surgery. Research on diaphragmatic hernias, liquid oxygenation and fetal surgery, and Dr. Wilson's quest for a biochemical signal that makes lungs grow, could lead to quicker and, hence, less costly cures.

Then there are whole new areas of science that could dramatically alter medical practice. "Way down the road somebody might not try to use machinery," Caplan says. "They might try to treat with genetic engineering."

Kent Lyon's T-shirt says "The party's ver." He's sitting in the second bedroom of his Taunton condominium, fax at one hand, telephone in his ear, doing business while Patrick whimpers/ A crib, with a Noah's ark quilt and Barney doll inside and an oxygen tank beside it, occupies the other half of the room. It is Aug. 9, and Patrick has been home from the hospital for three days. In their new house in Ware, Kent will have an office and Patrick will have his own bedroom.

For now, Patrick is crying and gagging and arching his back in discomfort after each feeding until, exhausted, he sleeps. The aftermath of the noon feeding spills into the 3 p.m. feeding which, in turn, spills into the 6 p.m. feeding. Linda holds Patrick often, to comfort him, feed him, and she doesn't mind because of all the times she couldn't hold him in the hospital. "I feel very comfortable with him. I know what I'm doing to calm him down," she says. "I wish it was easier on Patrick. I want him to know what normal is." "Having him home," says Kent, "wipes everything out." "It gets a little tense," says Linda. "The other day...maybe I was a little quick. I felt Kent was quick with me."

Dr. Wilson says this is the time when effects of marital stress set in, after the crisis, and he has seen a few marriages fail because of seeds of trouble sown during a child's illness. "They stick it out until the kid is basically better, and that's when the marriage falls apart," he says. "I can tell you it stresses every family out. That's why I kick families out. They can't keep a bedside vigil for four or five months."

On this day in August, his son newly home from the hospial and a home health care agency regularly providing 12 hours of nursing help daily, Kent does not admit to much stress.

"You have to look at the relationship," Kent says. "We never had problems in our marriage. It definitely hasn't distanced us. It has brought us closer."

On Aug. 26, moving day, Patrick is back in the hospital, this time for nine days. The mortgage broker, meanwhile, has told the Lyonses they don't qualify for financing, so they move to Linda's parents' home in Chicopee and reapply for a loan.

Patrick comes home on Sept. 4, without oxygen once more, but that doesn't last long, and when Linda takes him for walks she hangs a portable oxygen pack on his stroller.

It can get cramped in the Kotfilas' modest three-bedroom house, with Linda's parents and two brothers and, on weekends, one nephew. The home health care agency has trouble finding nurses, so there are too many nights without coverage when Kent comes home at 5 and sleeps until midnight, then takes the midnight and 3 a.m. feedings and watches television all night.

"Now I'm beginning to see where some of the couples can get into the stree portion," Kent says.

Slowly Patrick improves. He is down to one-eighth liter of supplemental oxygen a minute, as little as technology can deliver, and the fussy period after each feeding is shorter. He weighs 13 pounds, and when he bounces in his walker he bears weight on his legs.

The last Sunday in September, at St. Mary of the Assumption Church in Chicopee, Linda's home parish, Linda and Kent take Patrick for his baptism in the parish church, a full-fledged ceremony this time, albeit without water from the baptismal font because he already was splashed with holy water.

He is in his mother's arms, and he wraps his hand around his father's index finger. Kent strokes the baby's thumb as Rev. Francis Kennedy anoints Patrick's crown with the oil of chrism.

Gradually, during the previous week, Linda tried taking Patrick off oxygen, testing, checking his toe monitor, to see if he can maintain adequate oxygenation for an hour. He can, so he goes to the baptism, without oxygen, which means his godfather, Kent's brother-in-law and the godfathers of two other babies being baptized the same morning can safely hold lit candles.

Patrick's G-tube is hidden in the folds of his christening suit, so a stranger, seeing this baby for the first time, would not guess his difficult life or the drama of his earlier baptism.

His godmother, Linda's sister Lisa, slips the baptismal robe over his head, and Patrick brings a handful of fabric to his mouth and gnaws, a small thing, barely noticeable, but for a baby who has had no food by mouth for four months and who not long ago would gag if anything touched his lips, the comfort he finds in sucking the cloth is as much a symbol of hope as Father Kennedy's invocation of the mystery of Christ to "give them new life of baptism and welcome them into the holy Curch".

? QUESTIONS AND ADVICE ?

* Any suggestions for transitioning of the (G-tube) Button feeding? My daughter is 3 and a half and still getting the biggest share of her nutrition from Pediasure with fiber. She has been through feeding clinics, has OT and PT monthly. But she just does not have the desire to eat or drink and does not associate hunger pains with wanting to eat. Any other parents gone through this?
* I just found out we are expecting another baby. This was not planned but what will be, will be. Any suggestions for all the fears and worries we are facing?

Elaine Moats (mother of Kristin Moats)
2118 Batchelor St., Miles City, Montana 59301
(406) 232-5038

* I need help finding a formula for my son, Shane, now 3 years old. He's not gaining weight like he should, and feeding my mouth is not going too well (he has a Mic-Key button). He's allergic to all milk products, and we've tried everything; Pediasure (anaphalactic shock response), Tolerex, breastmilk, etc.. Now he's on Pregestimil, which is maintaining his weight, but not by much. Any advice out there?

Dawn M. Torrence

* I need information about bowel adhesions and bowel problems. I have a 10-month-old son, Jack, born with CDH.

Wendy Barkley
116 NE 48th Street, Lawton, OK 73507

Keeping-up-your-spirits Therapy

by Linda Allison-Lewis

Paperbook book (1991 Abbey Press)

1. Have a good attitude. It's healthier than a plate of carrots.
2. Cultivate your sense of humor. Laughter hides in strange places.
3. Make a list of your talents. You'll be amazed at yourself.
4. Think of a special friend. There's someone who loves you because you're you.
5. Keep things simple. You'll have more time for fun.
6. Forgive someone you're angry at. You'll feel light as a feather.
7. Forgive yourself in an instant. God does!
8. Make the best of what you have. You'll be amazed at its value.
9. See problems as opportunities. Don't dwell on them. Work at finding solutions.
10. Replace your fears with faith. And then let go.
11. Don't despair. A broken heart can mend if you give God all the pieces.
12. Don't run from the sad times. They can be opportunities.
13. Cherish your memories. Recall those that make you smile.
14. live without making judgements. Acceptance brings joy.
15. Abandon unnecessary guilt. It's extra baggage you don't need to carry.
16. Pursue inner peace. It's the deepest of all blessings.
17. Live in the moment. If you dwell on the past, you'll miss what's wonderful today.
18. Live in the moment. If you focus on the future, you'll miss the freedom of today.
19. Have faith in yourself. Refuse to believe in the word impossible.
20. Let loose of what you can't control. Serenity will be yours.
21. When you're having a bad tell, tell someone. A shared burden is always lighter.
22. Bask in the sunshine. It'll warm your heart.
23. Accept each part of yourself. God did a remarkable job.
24. Welcome new challenges. If God gives you a task, it will come with directions.
25. Slow down. There's no telling what you might miss.
26. Don't tear yourself down. You have innate worth.
27. Never compare yourself to another. You were formed with great precision.
28. Accept others without conditions. It's the very essence of love.
29. When everything is upside down, rest if you must but don't quit.
30. Accept suffering as a way of uncovering true values. You may not feel it, but you're growing.
31. Pray. God lifts the dark clouds when you pour out your troubles.
32. Start your day with faith. God will give you the strength to do whatever is necessary.
33. Set a small goal for yourself. Accomplishments feel good.
34. Offer someone love today. You'll be pleased when it returns to you.
35. Know that each day of your life is a gift. Have you thanked your Creator today?

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