



# TLC *Together Let's Cope*

A newsletter for and about parents of children in Neonatal Intensive Care

## Together Let's Cope – A part of the NICU Team

As parents to a premature baby, life has a lot of uncertainties. You are unsure if you should feel happy about the birth of your new child, or sad at the possibilities of losing them. You want to be angry but all you can manage to do is watch this team of professionals care for your frail, innocent, helpless, little child.

Many of the people you see are nurses. St. John's Neonatal Intensive Care Unit (NICU) (Moross Campus) has approximately 100 Registered Nurses who are specifically trained to care for premature infants. Some nurses have been with our unit for more than 30 years. Some of our staff has even had premature or special needs children themselves. All of this experience makes our nurses very understanding to the needs of families experiencing such a tragedy.

Among the nurses you will see Patient Care Technicians, Respiratory Therapists, Nurse Practitioners, Residents, and Neonatologists and many others. All of these professionals work together to meet the needs of your baby.

Together Let's Cope (TLC) focuses on the family. TLC is a values-based program dedicated to improving the well being and quality of life of families experiencing a neonatal crisis. Volunteers consist of parents who have all had babies in NICU or Special Care Nursery (SCN) and are now offering support to families who currently have

babies in NICU and SCN. By using peer-to-peer support as a mechanism for meeting the needs of families, TLC reaches out to parents as they reach out to their babies. Volunteer parents understand the day-to-day problems that come with having a hospitalized infant or providing care to a sick baby at home. When babies are born prematurely or have special medical needs, parents may feel overwhelmed. Feelings of anger, confusion, fear and guilt are not uncommon. Medical uncertainty, physical, emotional, and financial stress can leave parents feeling alone. Many times when a baby is born prematurely, there are no answers to the

reasons why. So parents feel very lonely and afraid; completely unsure of the future. TLC can help by sharing our stories and by reassuring families that even though this is a difficult time, you will make it through.

Our mission is to reach out to parents while they reach out to their baby. We know how complex life can be when you are juggling family life, work and now a sick baby. And with all of this comes a process of grieving. Some have lost part of their pregnancy; many have lost the type of birth they envisioned. All parents will loose ...continued on page 3

***“As you reach out to your child, TLC parents reach out to you.”***

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the experience of taking their baby home with them.

TLC volunteers can identify with all of this. As we visit with you at your child's bedside, we remember our own experience. We have ridden the roller coaster ride of good days and bad days and crying on the nurse's shoulder. We know the NICU is hard and growing takes time, but when your baby comes home, you will have a great accomplishment to be proud of. You will be equipped with the knowledge and skills needed to care for your baby.

Over the past twenty years, TLC has been providing families of neonatal patients a supportive and empathetic ear. In 1984, a friendship developed between two parents whose infant daughters were hospitalized in St. John NICU. Realizing they were a great support network to each other, they knew they could help other parents experiencing a similar crisis. When TLC became a formal support group affiliated with St. John Hospital it was one of the first hospital based parent-to-parent support programs for Neonatal Intensive Care in the country.

The services provided by TLC range greatly. Many parents need someone to listen. Parent phone support from a trained volunteer parent whose child had similar problems can listen to parents' needs and concerns. Volunteers provide helpful insight about how to cope and make practical suggestions to make daily life easier. Volunteers are also available to visit families at the baby's bedside. Parents can attend weekly meeting held in the Parent's Lounge while their baby is in NICU. This is a great opportunity to speak with other parents who currently have babies in NICU and to parents who have "been there" and can offer support and advice. TLC provides parents with a library of informational and inspirational books to borrow.

TLC will be with you as long as you need us; from birth to discharge and even to kindergarten. We are here to care for you, because when your baby has special needs, so do you.

## ***Did you know?!***

Preterm labor and delivery can happen to any pregnant woman. But they happen more often to some women than to others. Researchers continue to study preterm labor and birth. They have identified some risk factors, but still cannot predict which women will give birth too early. Having a risk factor does not mean a woman will have preterm labor or preterm birth.

### **Lifestyle and Environmental Risks**

Some studies have found that certain lifestyle factors may put a woman at greater risk of preterm labor. These factors include:

Late or no prenatal care, Smoking, Drinking alcohol, Using illegal drugs, Exposure to the medication DES, Domestic violence, including physical, sexual or emotional abuse, Lack of social support, Stress, Long working hours with long periods of standing

### **Medical Risks**

Certain medical conditions during pregnancy may increase the likelihood that a woman will have preterm labor. These conditions may include:

- Urinary tract infections, vaginal infections, sexually transmitted infections and possibly other infections
- Diabetes
- High blood pressure
- Certain birth defects in the baby

Researchers also have identified other risk factors. For instance, African-American women, women younger than 17 or older than 35, and poor women are at greater risk than other women. Experts do not fully understand why and how these factors increase the risk that a woman will have preterm labor or birth.

### **What Can Women Do?**

Remember, though, even if you have one of these risk factors, it does not mean you will have preterm labor. It just means that you are at greater risk than a woman who does not have a risk factor. Still, knowing you're at risk is scary. That's why it's so important that you know the signs and symptoms of preterm labor and take very good of yourself and your baby.

This is the best way to protect yourself and your baby against preterm labor.

# A Purposeful Journey

By Lydia Maola

Together Lets' Cope (TLC) became part of my life when my twin daughters were born. They were 26 weeks gestation and in need of a lot of care. Likewise, my husband and I needed a lot of support. Day after day we would come to visit our babies and just hope the uncertain future would be positive.

One particular day, waiting for us at my daughter's bedside was an invitation to join in on a Parent Support Group Meeting. I was apprehensive but I knew I needed to talk to someone who had been through this kind of tragedy. As I sat and listened



Holding Mya for the first time at 1 week old. She weighed less than 1 pound and was using a ventilator to breathe.

to other parents talk about their babies, I realized there was a light at the end of the tunnel. They talked about how excited they were to be bringing

their babies home. Some talked about having other children at home and the struggle of juggling babysitting with visitation. One mother in particular talked about what life was like after discharge and how her son had grown to be a healthy six years old. This mother was a TLC Volunteer and was coming back to share her story with all of us parents still struggling through the roller coaster of emotions in NICU. I remember she was very sympathetic to our worries and concerns. She even cried with one parent who was having a rough day. A few days later, I signed up to receive phone support. Now I was able to talk to someone directly about my daughters who really understood. My volunteer support parent had twins herself at 28 weeks and was wonderfully supportive. It was like she was in the unit with me; we had so much to talk

about. I am so thankful she became a volunteer; I needed her.



Mya and Amanda celebrating their 6<sup>th</sup> birthday with their little sister Sara (born full term).

About a year or so after my twins were discharged from NICU, I also volunteered to support families in NICU. I began with meetings and then started visiting parents at their baby's bedside. Soon, I was a phone support parent for another mother of a premature baby. All of this work became very important to me. I knew I could really make a difference in someone's life. As time went on, I became even more involved. Now that my twin daughters, Mya and Amanda are six themselves, I feel like I have rounded the corner.

Helping families process the grief of their particular situation has helped me grieve as well. I strongly believe in what TLC and St. John's NICU is doing for families, it worked for me.

Lydia Maola is a Patient Care Technician in NICU and also a volunteer for TLC. She is married and has 3 daughters.

# We Are Family!

TLC Volunteers are a family of a different kind. None of us are related by blood but rather by bond. We are a select few who have decided to come back and face our fears of the NICU and remember our pain to help someone else through theirs. All of our time is not spent in NICU or SCN. We also have lots of fun.



Pictured Above: Tricia, Noah & Payton Galbraith, Rhonda, Randy and Bailey McLarty, Lisa, Herb, Austin and Matthew Griebe, Clayton, Shawnee and Sebastian Ramseyer, Mike, Robyn and Alexis Schnieder, Sally, Rachel and Rebecca Chan, Mike, Lydia and Sara Maola.

◀ Each Summer TLC families come together and celebrate life. We have a cookout and play games at a local park.

At Christmas time, TLC children get a special visitor. Each child is given a gift from Santa. This is also a time of recognition for TLC Volunteers.



TLC Children (Most are NICU Graduates) pose for a picture with Santa in December 2001 (above) and December 2002(left).

# Our Scrapbook

March of Dimes **WalkAmerica**  
I'm helping to save premature babies.



▲(2004) Lydia Maola, (Mother of twin girls) Melissa Cattaneo (Mother of twin boys) and Pat Locklear (Grandmother of twin girls) pose for a picture while walking in the rain.



▲ 2004 St. John Moross Campus Goodwill Ambassador, Sebastian Ramseyer.



▲ (2000) NICU Staff and family members represent TLC and St. John NICU at WalkAmerica.



▲NICU parents walk in honor of their son, while he is still hospitalized. (2004)

For more information about the March of Dimes, visit [www.modimes.com](http://www.modimes.com)

# Family Centered Care

By Christine Wiseman, RN, BSN  
Clinical Nurse Manager, NICU

I feel that TLC is one of the best customer service initiatives that we as an NICU family have to offer our community. The grief that parents experience when they are going through the NICU experience is something that only other parents who have been through it can truly understand. The support that TLC offers to families is a vital part of our department and has far reaching effects for the families we serve.

Peer-to-peer support plays a significant role in how parents care for their infants. Parents can network and realize that they are not alone. They can find out information that may work for one family that may also work for them. It is wonderful that TLC offers peer support. I feel it helps improve the overall emotional well being of our families and provides family centered care.

Families of 20 years ago felt they had to hide their grief. It was as if they were ashamed they would not be able to cope with the stress of a baby born early or the loss of a pregnancy. Now we have so many resources to offer families when they are in crisis and they don't have to feel alone or helpless. Parents have the Internet at their fingertips and are information oriented. Parents want to learn about prematurity and how it will affect their baby now and in the future.

Technology has come along way since TLC began. First of all, medications help provide a better outcome for families. The introduction of Survanta, a synthetic surfactant, has made it possible for infants to come off the ventilator much quicker. This helps decrease the risk of oxygen toxicity that can be a factor in blindness. We are also seeing infants that would have been born at 24 weeks be

*"When I worked as a staff nurse in NICU I had an infant that I cared for over several months and became very close to his family. He had been diagnosed with BPD (Bronchiopulmonary Dysplasia) and died shortly after Christmas. Because he needed a large crib, he was in our isolation room. Prior to Christmas I came in and decorated his room with a small Christmas tree and decorations to make his room look like home. I always had a cassette tape playing for him. The music was instrumental and was from a children's book called "The Snowman." The night that I decorated his room his mom came in and was so touched that he looked so cozy and was getting to experience Christmas in his own way. Little did we know it would be the only Christmas he would ever experience? He died about 10 days after Christmas. I worked the midnight shift and told the staff to call me when he died no matter when it was. When they called me that morning it was shortly after I had arrived home from working midnights. I went back to the hospital and met his parents there. I remember sitting with his mom holding her and crying with her. As we sat there quietly the sound of the music was playing in the background; there wasn't any words spoken but there was a lot of love that filled the room."*

born at 31 or 32 weeks due to prenatal steroids. These factors are vital in the long-term medical outcomes of our infants. There is still limited information in the field of neonatology however; we have come a long way.

Secondly, we in the NICU want to reach out to them and help them be able to grieve and yet still be able to go on with their lives. I don't know how families in the past survived emotionally and I am grateful that we are in a much more resourceful time. Family centered care is an initiative we strive to

carry out diligently in NICU. Our skills help us care for the babies, our hearts help us care for the families.

Christine Wiseman began with SJH NICU in 1989. She worked in NICU as a staff nurse from 1989-1991 and returned as an Assistant Clinical Manager in 2002. Currently, she is Clinical Manager of NICU.

Christine is married and has two daughters, Chelsea who is 14 and Olivia who is 4 years old.



## Ask the Doctor

Featuring Dr. Deepak Patel, MD  
Neonatologist,  
St. John Hospital & Medical Center  
NICU

Emailed responses:

*You have always been a supporter of TLC, why do you feel it is important for families?*

TLC provides a forum for the families to come together and share their experiences about the newborn's hospital stay in a critical care unit. Parents expect the newborn to come home when the mother is discharged from the hospital. Newborn intensive care unit stay is hardly ever a planned event for the families. TLC provides an environment for families to express their feelings about this unplanned experience and gain some insight from the families who volunteer their experiences from prior hospital stay.

*TLC was one of the first hospital based support groups in the country, 20 years ago. Explain the difference between today's families who receive support and the families of 20 years ago who didn't.*

I have been a neonatologist for over fifteen years, so I can appreciate the trend in how families of today are helped to adapt to the stress of their little ones being in the critical condition. Often times families have used available resources to gain information, both medical and non medical, pertaining to their newborn's condition. They are better prepared for taking care of infants at home through [the] TLC support group.

*Technology has come along way since TLC began. Outside of the advancement of medicine, in your opinion, is there a medical difference in outcome for the babies whose families were supported? Does peer-to-peer support play a role in how parents care for their babies?*

Beyond the technological improvement in medicine support groups help families to be better prepared to handle the stress of hospital stay. An informed family is better prepared to follow [the] newborn's progress and their bonding is less hampered. Clearly, bonding between the newborn and parents is of paramount significance in terms of weight gain, and physiological stability.

Locally at our institution and nationally, support groups have made a tremendous impact in guiding us how to become family centered where we are aware that we take care of the newborn and the families.

*Throughout your career, you have dealt with many families. Is there a family that stays close to your heart, a child that you will always remember, or a miracle story of a child who defeated the odds? Please share it with us.*

! (Editor's Note: Dr. Patel couldn't pick just one story; they all stay close to his heart.)

Dr. Patel began at St. John Hospital in 1988. He is married with three children, 2 girls and a boy.

## How Can I Help?

TLC has many different programs available to those who want to help.

*Volunteer:* Parents who have been through the NICU experience are welcome to return and support families currently in NICU. Recruitment and training sessions are held annually.

*Book Donation:* Donating a book to the TLC Lending Library is the most effective way to impact the lives of families. Whether a specific book is donated or money is provided for materials, we appreciate the contribution.

*Fundraising:* Annually TLC holds a Mom to Mom Resale Fundraiser. We rent out table to families wishing to sell items they no longer need. Refreshments are available for purchase also.

*Listening:* If someone you know is experiencing a neonatal crisis, you can simply help by listening to their story. We all love to feel validated, especially when we are hurting. By holding someone's hand and allowing them time to grieve, you may be helping more than you know.

**Please send all correspondence to:**  
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313-343-3683  
Attn: Christine Wiseman, RN

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**Material Resources**  
*Mother Baby Journal*  
*March of Dimes*

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### **NEXT ISSUE: Full Term Babies In NICU**

Together Let's Cope is a support group for families in Neonatal Intensive Care that is values-based and dedicated to improving the well-being and quality of life of families experiencing a neonatal crisis. TLC utilizes peer-to-peer support as a mechanism for meeting the needs of families. Services include discussion group meetings, bedside visitation, phone support, lending library, and much more.

TLC Newsletter is published by Together Let's Cope, a volunteer non-profit family support program in the NICU. Its purpose is to educate, inform and to recognize the important contributions made by our TLC volunteers. Please consult your child's physician before initiating any changes in your child's care.