



TeleFamilies Times

Volume 2, Issue 1

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SUGGESTED WEBLINK:



www.gottransition.org

The website serves as an information exchange about health care transition, particularly for youth with special health care needs. There are resources posted under the "Families" link, with more pending this month. More important, there are many resources for your teen under the "Youth" link, including a Facebook page, videos and old-fashioned reading material.

"Believe with all of your heart that you will do what you were made to do"

- Orison Swett Marden

Another TeleFamilies Milestone

As of February 1st, all families have been randomly placed into one of the three study groups. After you are placed in a study group, the 'Baseline Survey Packet' is mailed to you. It arrives in a large white envelope and contains a colored folder, along with the survey packet and an addressed, stamped envelope. This survey is very important. Thank you for taking the time to complete and return the survey.

We realize how busy life can get. If the survey packet is still sitting in your stack of mail, it is never too late to send back. Sometimes the most

difficult part of completing the survey is finding the time to do it. We can help by meeting you at home, work or any other location and going through the survey with you. Please call Sara at 612-625-9127 and tell her what we can do make finishing the survey easy for you.

All three groups are equally important in helping us understand the impact of TeleFamilies on your child and family. If you are not sure which study group you are in, please call or email Sara at 612-625-9127 / telehlth@umn.edu.

Stan Finkelstein, PhD

Professor and Program Director

The 'Art' of Transition by Cathy Erickson

I completed the first formal phase of transition with my daughter with special needs the year she turned 20. Yes, we were a little late, but like other parents of teens, I began thinking about my daughter's transition process many years earlier.

Transition planning with schools and social workers is aimed at maximizing independence (learning, living, working as young adults when possible). There is also the transition from pediatric to adult health care services. There are emotions - we loved our pediatrician! Fears - who can do the same great job? And finally, the excitement of graduating!

If your child is medically stable, good planning and coordination of care are still important. If your child has significant health needs, the planning involves more discussions, decisions and

even greater pediatrician involvement. If your child can understand and participate, what are the resources for them? Where do they fit in to the planning? Talking to your pediatrician is a key piece of the process.

We used a few checklists to guide us (learning to take your own medications, set up the pill box, place a pharmacy re-order), but the biggest step was interviewing a new provider and making the big decision. We survived! She loves her new doctor and he measured up just great when the first visit involved an unexpected medical issue.

There are resources to help guide you through transition. The National Health Care Transition Center has a great website, resources and a program called *Got Transition?* (see the suggested weblink on this page for more information.)

Meet Wendy Looman, PhD, RN, CNP University of Minnesota Study Investigator

Wendy Looman is a nurse with an interest in quality of life for children with special health care needs and their families. Dr. Looman is an associate professor in the School of Nursing at the University of Minnesota. She also works as a pediatric nurse practitioner in the cleft palate and craniofacial clinics at the University of Minnesota. Her research has included studies of how community connectedness can affect health for families and children. She has a special interest in the role of the

advanced practice nurse in providing care for children with complex health needs. Wendy moved to Minnesota in 2003 from Michigan, where she grew up in a family of racecar drivers. When she is not working, she enjoys playing fetch with her dog, Locket, who has a disability (but doesn't know it).



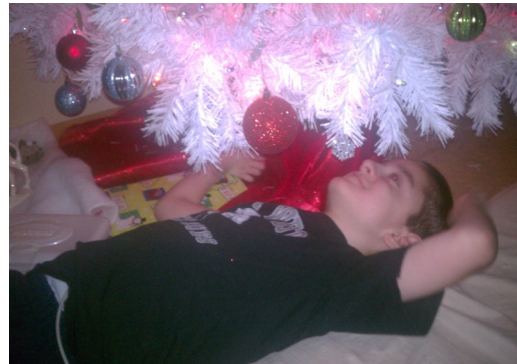
"Our greatest glory consist not in never falling, but in rising every time we fall"

- Oliver Goldsmith



The TeleFamilies Team:

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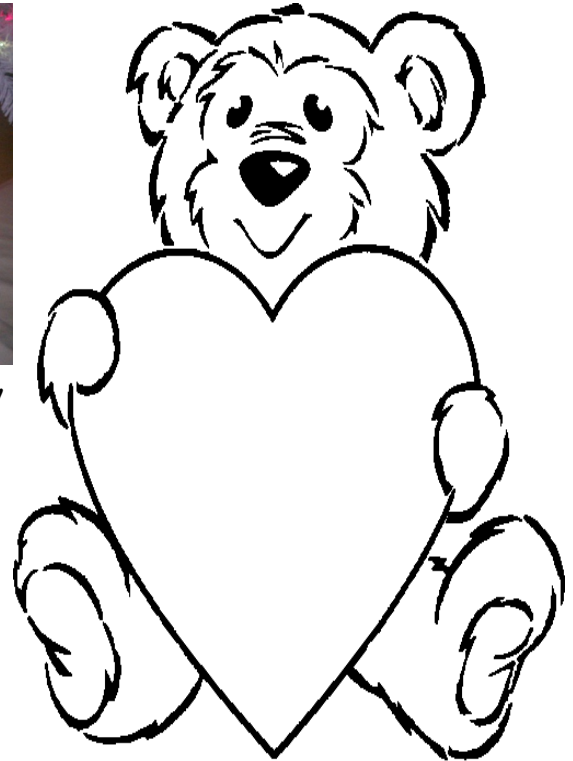
Patrick's new favorite thing to do!

Photo provided by Mom

Do you have a picture, artwork or written material that could be shared in upcoming newsletters? Feel free to send us any item (See Contact Information below for addresses). We look forward to hearing from you!

Coloring page from: <http://neverland-tinkerbell-coloring-pages.blogspot.com/>

Kids Corner



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