Texas Newborn Screening News

Volume 1 Issue 4  

Spring 2011

For the past two years, staff of the Texas Early Hearing Detection and Intervention (TEHDI) Program have been revamping educational materials and creating new brochures and fact sheets. The look of the TEHDI Program has changed with a new teddy bear logo and a consistent color scheme. Parent and provider focus groups and TEHDI stakeholders helped guide the TEHDI Program with suggestions for layout design and content. The materials can be broken up into intended audience; beginning with prenatal providers through early intervention service providers. The following materials, in both English and Spanish, are available upon request.

<table>
<thead>
<tr>
<th>Name of Material</th>
<th>Target Audience</th>
<th>Intention</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3-6 Guide</td>
<td>All Providers</td>
<td>Flow chart for providers to understand the hearing detection and intervention process.</td>
</tr>
<tr>
<td>FAQ Sheet for Providers</td>
<td>Medical Home Providers</td>
<td>To answer some of the commonly asked questions.</td>
</tr>
<tr>
<td>Brochure for Health Professionals</td>
<td>Medical Home Providers</td>
<td>To provide an overview of the TEHDI program.</td>
</tr>
<tr>
<td>PCP Resource Guide</td>
<td>Medical Home Providers</td>
<td>A comprehensive guide to the TEHDI program.</td>
</tr>
<tr>
<td>Information for Parents to Be</td>
<td>Parents</td>
<td>To provide information on hearing screening prior to birth.</td>
</tr>
<tr>
<td>Newborn Hearing for Midwives</td>
<td>Midwives</td>
<td>To educate on the newborn hearing screening process.</td>
</tr>
<tr>
<td>Sounds of Texas (Eng/Sp)</td>
<td>Parents</td>
<td>To provide information in the hospital regarding the newborn hearing screen in the hospital.</td>
</tr>
<tr>
<td>Hearing Screening Result: Did Not Pass (English)</td>
<td>Parents</td>
<td>To provide information and next steps when a newborn does not pass the hearing screen.</td>
</tr>
<tr>
<td>Hearing Checklist for Parents (Eng)</td>
<td>Parents</td>
<td>To provide important speech and language milestones to help detect late onset of hearing loss in children.</td>
</tr>
<tr>
<td>After the Hearing Screen: More Tests (Eng/Sp)</td>
<td>Parents</td>
<td>Provide more information regarding the diagnostic evaluation after a newborn does not pass the outpatient screen.</td>
</tr>
<tr>
<td>Genetics and Hearing</td>
<td>Parents</td>
<td>Provide more information regarding genetic testing after a newborn is diagnosed with hearing loss.</td>
</tr>
<tr>
<td>Audiology Desk Tool</td>
<td>Audiologists</td>
<td>Guide for reporting hearing results in the TEHDI system. It is a small booklet that can sit on a desk, like a daily calendar.</td>
</tr>
<tr>
<td>Audiology Resource Guide</td>
<td>Audiologists</td>
<td>This is a comprehensive guide to the TEHDI program for audiologists.</td>
</tr>
</tbody>
</table>

For general information regarding the TEHDI Program contact:  
Mary Gwyn Allen, TEHDI Coordinator  
(512) 458-7726  
marygwyn.allen@dshs.state.tu

To order TEHDI educational materials contact:  
Melissa Nagle, TEHDI Program Specialist  
(512) 458-6616  
melissa.nagle@dshs.state.tx.u
Newborn Screening Medicaid/Charity/CHIP demographic forms with serial numbers in the range of 10-0150000 through 10-0300000 were printed without text boxes for the Medicaid number (see example below). Although there are no boxes for individual digits, the Mother’s Medicaid Number must still be written in the blank space below the printed words “Medicaid No.”.

Forms Missing Text Boxes

Forms Correctly Displaying Text Boxes

Call the Newborn Screening Laboratory at 1-888-963-7111 X7333 with any questions regarding the Medicaid Number.

Newborn Screening: It’s NOT Just “PKU”

Confusion among doctors, hospitals and parents is created when newborn screening tests are called “PKU tests” or “PKU’s”. The term “An abnormal PKU” is often used and misinterpreted as an abnormal result for any of the 28 screened disorders. Parents look for information on PKU, when in fact, another disorder could be in question. To avoid misleading parents and the NBS Program, please educate parents and your staff to refer to the test as a “Newborn Screening Test” rather than a “PKU”. Thank you.

Texas Newborn Screening Program
Meet Our New Newborn Screening Ombudsman, Patrick Clynch

We are pleased to introduce our new Newborn Screening Ombudsman, Patrick Clynch. Patrick comes to the Newborn Screening Program from the DSHS Laboratory where he served as the Training Coordinator. He has a Masters in Educational Psychology and is a Licensed Professional Counselor. He has extensive experience in providing counseling and casework services for children, adults and families in a variety of settings.

As the Ombudsman with the Newborn Screening Program, Patrick will be able to apply the experience and associations developed while working at the DSHS Laboratory into assisting any NBS system participant with any problems they may have regarding NBS processes. The combination of Patrick’s education and experience in counseling psychology is a good fit for working with the Newborn Screening Program by assisting individuals and families in obtaining benefits and medical treatment services by working with health care providers, hospitals, and clinics for example.

Patrick is an avid outdoorsman and likes to bike, camp, kayak and fish, and recently began learning to play the Ukulele. For over 15 years, Patrick has provided volunteer labor for nature trail maintenance and construction in private, local, state, and national parks.

Please join us in welcoming Patrick to the Program. For assistance with NBS problems you can reach Patrick at patrick.clynch@dshs.state.tx.us or (512) 458-7111 ext. 3386.
DSHS Recommended Flow for Adolescent Females with Elevated PHE Levels

Some girls are detected at birth as having an elevated phenylalanine level. When the phenylalanine elevation is mild (benign hyperphenalamia) the child may not need treatment. However, these elevated phenylalanine levels can be harmful to a developing fetus if she becomes pregnant. Use the following flow as a guide for adolescent females with PKU or benign hyperphenalamia.

### Elevated PHE Levels Flow

- **No PHE Restriction**
  - Obtain Current PHE Level
    - Normal
    - Moderate or Elevated PHE
      - Perform PHE Level Prior to Pregnancy

- **PHE Restricted Continue PKU Monitoring**
  - Initiate/Review
    - Dietary Counseling Foods & Supplement Options
      - Initiate/Review Discussion of Reproductive Basics:
        - Anatomy
        - Menses
      - Discuss Effect of Elevated PHE Levels on Fetal Development and