



# Hands & Voices Collaboration with Hospital Screening Programs to Address Loss to Follow Up

Jeanne Hollabaugh, Laurie Nelson, and Lisa Kovacs

# Guide By Your Side is a program of Hands & Voices



- To empower parents to make their own decisions that are right for their child and family
- To encourage and assist families of children who did not pass screening to return for critical follow up
- To provide EARLY, comprehensive, unbiased information and support to families of children with confirmed hearing loss



# Components of GBYS

## Follow Through (Pre Dx)

- at referral on inpatient hearing screening
- at referral on outpatient or 2<sup>nd</sup> hearing screening

## Direct Parent Support (Post Dx)

- immediately after identification
- ongoing as requested by family

## Representation at the Systems Level

- EHDI Advisory Committee
- EHDI outreach activities

## FT Parent Guides have:



- formalized on-going training and affiliation with H&V.
- knowledge of state EHDI system, referral process and options for follow up.
- sensitivity to range of emotional responses that families experience.
- knowledge of joys and challenges of raising a child who is deaf or hard of hearing.

## FT Parent Guides contact families and :



- share with the families the importance of follow up **from a perspective of someone who benefited** from NBHS.
- encourage families to move forward; reinforce consistent message of importance of getting to next appointment without causing anxiety.
- answer questions; direct audiological and medical questions to appropriate professional.



- ask if baby's next appointment is set.
- facilitate the process of follow up: finding diagnostic centers, helping make the calls, explaining what to expect, overcoming language and transportation barriers.
- discuss steps with a family, not to take the steps for them.
- help families discover that **they** can help **themselves**, not to take that responsibility for them.

# Arizona - Follow Through



- Hospitals are assigned a FT Guide.
- FT Guides collect information from hospitals on infants who don't pass screening
- FT Guides provide hospitals with FT cards.
- FT Guides call families.

# GBYS FT Postcard



Mom, I just had my hearing screened and I need to have my ears re-checked in two weeks.



It is very important to bring me back to the hospital or to an Audiologist. I might have a hearing loss. Someone may be calling you to answer questions and help get my ears checked. If you don't want someone to call you, please call 1-866-685-1050.



Arizona Department of Health Services is partnering with Guide By Your Side to assist families through the screening process. A Parent Guide will be contacting you. If you prefer not to be contacted, please call the Program Coordinator at 866-685-1050.

# GBYS Program Coordinator



Jeanne Hollabaugh,  
GBYS Program Coordinator  
Hands & Voices Secretary

P.O. Box 64091

Tucson, AZ 85728

Phone: (866) 685-1050

Fax: (520) 843-2070

[jhollabaugh@azhv.org](mailto:jhollabaugh@azhv.org)

# Collaborations

- Arizona Department of Health Services
- The EAR Foundation of Arizona
- Arizona EHDI
- Arizona Hands & Voices



# Wisconsin - Follow Through



- Hospitals are assigned a FT Guide.
- FT Guides provide hospital staff with talking points: “Let’s Talk About the Guide By Your Side Follow-Through Program”
- FT Guides provide hospitals with FT cards
- FT Guides contact families

# GBYS FT Program Note Card



**"Mom, I just had my hearing screened and I need to have my \_\_\_\_\_ ear/s re-checked in two weeks."**

**"Please don't worry. This is only a screening but the doctor says that it is very important that you bring me back to the Hospital or to an Audiologist in a week or so. They also said that there is someone you can talk to if you want to learn more or need help getting my ear/s re-checked."**

# GBYS Follow Through Coordinator



Connie J. Stevens  
GBYS Follow-Through Coordinator  
Wisconsin Sound Beginnings (Rm. 351)  
Wisconsin Department of Health Services  
1 W. Wilson, P.O. Box 2659  
Madison, WI 53701-2659  
Office: 608-266-0917  
Fax: 608-267-3824

[Connie.Stevens@dhs.wisconsin.gov](mailto:Connie.Stevens@dhs.wisconsin.gov)

# GBYS Program Coordinator

Laurie Nelson, Parent Liaison  
GBYS Coordinator

Hands & Voices Vice President

WESP-DHH Outreach

1300 Industrial Drive

Fennimore, WI 53809

608-822-3756 - phone

608-822-3828 - fax

888-656-8556 - toll-free

[laurie.nelson@dpi.wi.gov](mailto:laurie.nelson@dpi.wi.gov)



# Collaborations

- Wisconsin Dept. of Public Instruction
- Wisconsin Dept. of Health and Family Services
  - WI Sound Beginnings (WSB) (EHDI program)
  - WI Birth to 3 Program
  - Office for the Deaf and Hard of Hearing
  - Regional Centers for Children with Special Health Care Needs
- Wisconsin Families for Hands & Voices
- WI Personnel Development Project (University of WI)



# Indiana - Follow Through

## Role of the Parent Consultant



- Works collaboratively with EHDI staff to ensure:
  - that families of children who refer from UNHS due to a “did not pass” or “passed, but at risk for hearing loss” results receive contact (letters, phone calls)
  - Contacts families within 1 week of receipt of an EARS alert to ensure that audiological follow-up is scheduled or in process
- Uses the EHDI Alert Response System (EARS) to document all contacts with families and professionals



- Shares information on navigating through the process from a parent's perspective



- Links families to audiology services, EI and other services that may be needed and fall within the domain of short-term EHDI follow-up

- Participates in outreach activities conducted by the EHDI program which target consumers and professionals (i.e. EHDI Family Conference, Early Intervention forums, EHDI trainings)

# Did not Pass Follow up Protocols



	Step Name	Sequence	Instructions	Response	
	DNP - Call Parent (immediately)	1	Call parent to encourage follow-up, provide FS phone number, and provide EHDI number for additional assistance as needed.	Phone	X
	DNP-Send 1st Mother and Physician Letters (immediately)	2	Go to Response Center. Select 1st letter Did Not Pass. Save letter to batch.	Letters	X
	DNP-Send 2nd Mother letter (45 days)	3	No follow-up, DAE, or reports have been received by EHDI. Select 2nd letter.	Letters	X
	DNP-Make Phone Call to Parent (45 days - same time as 2nd letter)	4	Contact parent to determine if testing is complete or scheduled. If no response, reassign to audiologist	Phone	X
	DNP-Make second call to PCP (90 days)	5	No f/u results have been received at EHDI program. Select phone call and record notes.	Phone	X
	DNP-Send SPOE Email (120 days)	6	Email SPOE contact to determine if f/u has been completed	Email	X
	DNP-Review file and set status (when child is one year of age)	7	Review file and attempt one last family contact if appropriate. If no contact occurs, classify LTF/D. If parent refusal, note on CHIP and close file.	Phone	X

# GBYS Program Coordinator



Lisa Kovacs

GBYS Program Coordinator

Indiana Hands & Voices

3100 Meridian Park Dr. Suite N Box 289

Greenwood, IN 46142

888-815-0006

[lkovacs@isdh.in.gov](mailto:lkovacs@isdh.in.gov)

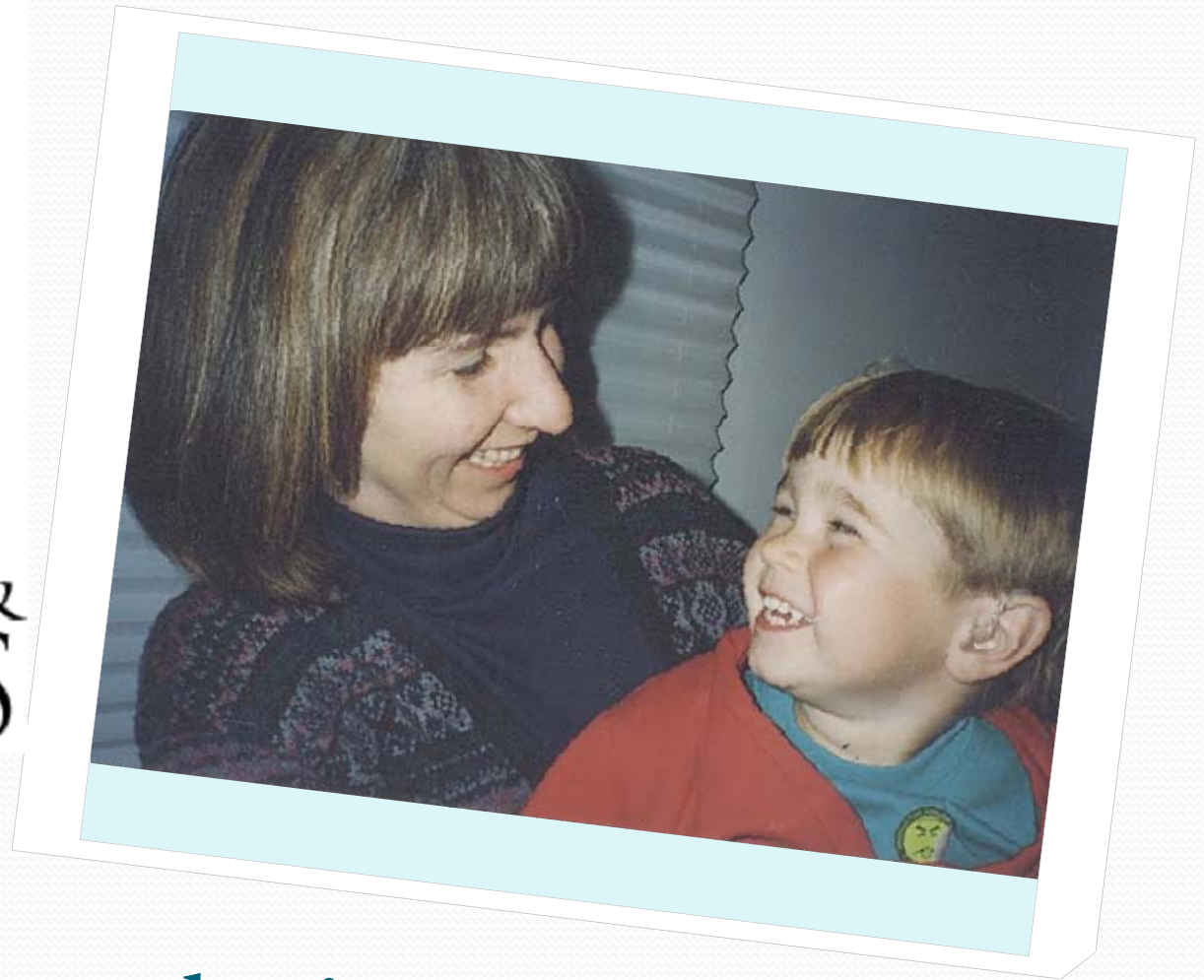


# Loss & Found

- DVD developed by Hands & Voices
- Can be shown to families when an infant doesn't pass newborn screening



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[www.handsandvoices.org](http://www.handsandvoices.org)

