



Follow up

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Sally Hiner

From: Nash, Claudia [Claudia.Nash@Illinois.gov] **Sent:** Tue 7/27/2010 11:42 AM
To: Sally Hiner
Cc:
Subject: LT Follow up
Attachments: NBS Birthday (Annual Report) Form for CF.doc(40KB) NBS Birthday (Annual Report) Form for all other Met.Disrev.doc(42KB) Sickling Annual Letter.docx(16KB)

Sally,

Attached are the forms Illinois uses to collect information on an annual basis for all children diagnosed through newborn screening. These were developed in conjunction with our subspecialists.

There are specific forms for CF (with less information collected per a recommendation from the CF Centers); sickling disorders (more detailed info); and one form used for all other disorders. We do ask some basic questions about education.

Our process involves sending a form for each child to their specialist annually in the month of their birth-age 15 years, which in IL is between 4,000-5,000 children each year. We then resend the form if it is not returned in a certain time frame, and then call the specialist if the form is still not returned. This nets us probably an 80% return rate.

If the specialist indicates they no longer see the child, we then contact the primary care provider on record. If the PCP is no longer seeing the child, we then search various databases for the most current address for the family. We then send a letter to the family asking for the name of their PCP. If no response, we then refer the case to a local city/county public health agency to make a home visit to the family. If a physician is identified by the home visit, we then will redirect our letter to that physician and update our database so that the annual request will be generated the next year to the proper physician.

As the child gets older; due to families moving, etc, we generally have less luck tracking them especially with endocrine disorders and hemoglobinopathies.

When the forms are returned, our staff enter the information into our database. This entire process is very labor intensive, as you can see.

Ultimately we hope to obtain this information through an electronic exchange with the specialists when we deploy a new data system.

The primary outcome of this process has been assuring that newborns/children are linked with specialty providers and are in compliance with necessary treatment. Unfortunately, we have not been able to do much with the aggregate data we collect, but it is available for review by subspecialists.

I guess I would caution our group to keep in mind the resources needed to conduct any type of monitoring and to have a plan for how they will utilize the data collected.

Thanks, Claudia

Please note my address has changed

Claudia Nash, M.S.
Genetics Program Administrator
Illinois Department of Public Health
535 W. Jefferson St., 2nd Floor
Springfield, IL 62761
217-524-4900
217-557-5396 (fax)
claudia.nash@illinois.gov