

## Editorial

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***Please Note:*** *The strong-worded comments below are not directed at any of our Families or Professionals ~ we ALL KNOW how important Expanded NBS is! These comments are directed at anyone that calls this type of screening 'defect testing' and to those that are working toward keeping the screening from being mandated in various states. The 'defect' comment was made a few months ago by a health professional (that should know better!) and this Editorial is MY personal outrage at that argument against expanding NBS. DLG*

Although a lot has been happening on the NBS front across the country, things are moving rather slowly. The frustration comes when the political process and money and turf issues get in the way of saving lives. Yet, as shown on the TV News, there are **some times when things move faster than usual in that political process. An example is the NATIONAL MANDATING of the Amber Alert ~ it's GREAT that having that will SAVE LIVES ~ but SO WILL EXPANDING Newborn Screening!** Many of us in various organizations have been working out front or behind the scenes for YEARS on this issue but in only 3 months the Amber Alert was passed and MANDATED across this country. My question is: What makes that issue so much more important than expanding NBS that it can be moved through Congress so quickly and unanimously? A question that is probably not politically correct to even ask and one that we will probably not get a full answer to ~ but I feel is worth asking.

Of course, critics of expanding NBS will be quick to voice their opinion on this issue and then some. **For those critics of Expanded Newborn Screening that believe this type of screening is really 'un-consented genetic testing to create a database, track and research defective children'** (these are paraphrased comments taken from comments made by a health professional who tried to derail expanded NBS in MN) ~ **it is NOT! I was APPALLED** at the news release this health professional from the Citizens' Council on Health Care posted on her website **calling NBS 'Defect testing' and calling our children that are identified 'LESS THAN PERFECT!'** If you've ever experienced the **ramifications (death or major LIFELONG medical complications) of NOT knowing** your child has/had one of the 30+ disorders that can be screened for using tandem mass spectrometry, **you would KNOW** that it's **NOT** a matter of testing in order for some medical/insurance/government group to track/exploit your family's medical history!

Expanded NBS is also not trying to ascertain (by genetic testing) whether someone will be predisposed to some disorder/disease process in the **FUTURE** because they may carry a specific gene ~ **it is a SCREENING for SILENT and INVISIBLE disorders that if not detected AT BIRTH may not give that infant a CHANCE TO LIVE beyond the first days of life if they are not treated immediately!** These are also not disorders that a person will develop because of environmental or behavioral factors (i.e. developing cancer due to asbestos exposure or smoking) ~ **they are BORN with these disorders ~ and whether or not Expanded NBS gets fully mandated across this country, these**

**babies are STILL GOING TO BE BORN ~ and many will continue to die just because some critic(s) believe it's not right to screen for them because they think families shouldn't be subjected to such testing or that their screening card shouldn't be kept on file for several years.** They state that privacy is an issue ~ but if you read Lynne's article on HIPAA in this issue, you will learn that **privacy is taken into consideration and there are laws to protect it!** States that are currently adding the expanded screening are also implementing their own privacy regulations in addition to what the federal government has already implemented so **the privacy issue really isn't an issue in my opinion.**

As for consenting to expanded screening at birth versus having it mandated and being **automatically** done on all newborns (unless for religious objections) ~ **I would have given anything to have had the medical professionals just do the Expanded NBS in 1983** (if it was available) when our daughter, Kristen, was born ~ unfortunately, the screening test wasn't fully developed at that time and our daughter died suddenly because we **DIDN'T KNOW** she had MCAD, one of the many disorders that can be screened for AND treated through diet and medication IF detected EARLY. And if her NBS bloodspot had been saved **we may have learned about her MCAD a lot sooner than 1 year AFTER her death!**

So **to ALL the critics out there** ~ This issue of expanded NBS is **NOT** about trying to place your **NOT SO PERFECT LABEL** on infants or about the government having a hidden agenda of creating a 'defect inventory' of families with genetic disorders ~ **it's about SAVING LIVES** ~ **OPEN YOUR EYES and your HEARTS!**

Deb Lee Gould, Director