

FOD Director's Stand on NBS Labs for Expanded Screening

Along with my statement on our site's NBS page, I also wanted to expand on **WHY** I have taken this stand. And YES, I am far from 'politically correct' when it comes to saving babies ~ so I'll warn you that some may be offended or put off by my comments and opinions. But I can live with that ~ I don't have time to worry about others not liking my point of view ~ **saving lives is a higher priority for me.**

I've quietly advocated (mostly in print) utilizing a Regional Testing Lab format for many years, since the early 90s. However, over this last year, and especially over the last several weeks, I have become more VOCAL about my feelings on getting expanded NBS MOVING and out of the let's talk, let's wait and see, let's not screen until this or that, let's not screen for disorders that may not have a so-called 'effective treatment' (of course **you can't DEVELOP EFFECTIVE TREATMENTS until the babies are IDENTIFIED ~ and you DO that thru SCREENING!**) or let's not screen for disorders that are CURRENTLY considered fatal because having to tell the parents would be difficult!

Well, you know what's even **MORE DIFFICULT** folks? **Having to bury your own child and NOT KNOWING** that he/she had a specific disorder (I did that 17 years ago with my own daughter!) **or having to live with the major residual medical complications of NO or LATE DIAGNOSIS** ~ and then for some moms, having to live with being **SHAMEFULLY and WRONGFULLY LABELED** as having Munchausen by Proxy (some accused by professionals/Drs that haven't even SEEN their children!) all because they have been trying desperately to find a diagnosis (which is already FAR TOO LATE!) for their constantly sick child that has LOTS of Drs visits and hospitalizations ~ **THAT is BEYOND DIFFICULT!**

It really galls me that many are battling (in state committees, legislatures etc) over which disorders SHOULD or should NOT be tested for (even though they CAN be screened for), and making decisions NOT to include certain disorders because **THEY THINK** parents wouldn't want to know if it was a disorder that hasn't YET been treated effectively. Again, folks, **HOW DARE ANYONE MAKE THAT DECISION FOR ME OR ANY OTHER PARENT!** It's somewhat analogous to some HMOs that have LAY people making TREATMENT decisions for the person and telling them that they CAN'T have some MEDICAL procedure!

Even if there wasn't a positive prognosis for a particular disorder you better believe **I (and many other families I've spoken with) would WANT TO KNOW ANYWAY** so I/they could spend what little time there may be with that infant, as well as to be able to grieve WITHOUT having the complicating factors of an UNKNOWN cause (unknown ONLY because someone made that decision FOR us not to screen for that screenable disorder ~ **yet I/we would find out on autopsy!**).

Let me tell you WHY I advocate a regional system:

I am DISGUSTED at having to respond to MANY calls from grieving and angry families that have just experienced the NEEDLESS death of their young child (especially when they find out these are disorders that CAN be screened for ~ even if their state DOESN'T test for them yet ~ and that most DO have effective treatments) or from ones that are dealing with LONGTERM medical problems of 1, 2 and for some, 3 children, ALL because their child was not tested/diagnosed/treated at birth!

I am DISGUSTED and FRUSTRATED at WAITING for EACH STATE to debate whether to make the decision to screen, then debate over money and which disorders to screen, then buy their own instrumentation, then train personnel to EFFECTIVELY INTERPRET these tests, ...and the List goes on ~ in the meantime **I keep getting the above CALLS!**

If a Regional format was used, **QUALITY CONTROL over say for instance 5-7 Labs would be alot easier than keeping an eye on 50 or 51 DIFFERENT LABS** ~ and ALL doing their own thing as far as deciding which disorders to screen for. I advocate that **Regional Labs do UNIFORM and UNIVERSAL SCREENING so that EVERY STATE is on the SAME PAGE!**

But here's where the problem lies with this issue as well as with MANY human issues ~ **money, politics and turf all get in the way of JUST DOING WHAT NEEDS TO BE DONE ~ SAVING LIVES!** Right now, we are in a state of INEQUALITY depending on which state you happen to live in ~ and the **BABIES and FAMILIES PAY THE PRICE** ~ that is NOT right!

I don't have all the answers (what parent does?!) and I certainly don't have a foolproof plan to set up these Regional Centers [although, in my opinion, there are already **3 major NBS Labs EFFECTIVELY FUNCTIONING like Regional Centers doing supplemental and/or comprehensive screening, as well as Diagnostic Testing when necessary AND researching new developments** in screening techniques etc, AND two of the three Labs also have the **capability to offer families either new treatment research studies/follow-up or long-term clinical care follow-up/consultation for several of the disorders**] ~ but one thing I DO know is that we have to **THINK MORE OF THE CHILDREN** instead of placating egos and being politically correct and bickering over what I see as ridiculous turf issues **WHILE BABIES DIE!**

And don't tell me there's a 'PROCESS that NEEDS to be followed' ~ **THESE BABIES DON'T HAVE TIME FOR PROCESS!**

WAIT for EACH state's PROCESS? With ALL the above issues we MAY end up UNFORTUNATELY having to do that, but you better believe **I won't stop giving a VOICE TO THE CHILDREN ~ THEY CAN'T AFFORD TO WAIT for EACH state** to do their own cost benefit analysis etc just to prove the expanded testing would be worth it! **EVERY newborn's life is worth it!**

Those of you that have already had a child die or one/several medically impacted because of NO screening or not KNOWING that there IS testing available, I believe you KNOW where I'm coming from. But for others that may think my comments are from being some 'over emotional' mom ~ go ahead and think that ~ damn right I'm emotional and I'll KEEP being emotional until **EVERY NEWBORN IN THIS COUNTRY IS SCREENED UNIFORMLY, UNIVERSALLY, and with FAST TURNAROUND IN SENDING SPECIMENS and GETTING RESULTS so EARLY TREATMENT CAN BEGIN** and I believe that would **MOST EFFECTIVELY be done THRU A REGIONAL LAB FORMAT!**

I welcome any and all comments.

Take care...

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