Your Child Has Early Onset Progressive Scoliosis:

The Good News and the Hard News

Welcome!

So, your baby or young child has been diagnosed with **Early Onset Scoliosis- (EOS)/Progressive Infantile Scoliosis- (PIS).**

You have found the **Infantile Scoliosis Outreach Program-** (**ISOP)** and/or the private Facebook group **Early Onset Scoliosis and Mehta Casting**.

You're on the right track, in the right place advocating for your child.

There are some things that no parent wants to say to newcomers to this journey, because no one wants to be the bearer of difficult news.

(**Note:** This is written by an experienced EOS parent, not a doctor or medical professional, and every scoli child is unique.

All advice here is based on our own medical experience and much gathered information from scoliosis groups and experienced families for over 15 years. "Anecdotal evidence," as they say in the medical world.)

First, the really, really good news: Heather Hyatt Montoya founded ISOP and this group, and was responsible for bringing **Dr. Mehta's** early approach to EDF (elongation, de-rotation, flexion) casting to the U.S.

Mehta's Growth Guidance Casting (MGGC) was not always available in the U.S. and we are the lucky ones who have a chance at this method helping and/or curing our children with this rare, dangerous form of scoliosis today.

Countless children have already been “cured” or moved out of surgery range with only non-surgical Mehta casting, followed by temporary bracing.

We also have internet searches and social media now to find each other, share our experiences and offer support.

The bad news is that although many of us have been brought up to believe that our doctors always know best, there are still many otherwise excellent pediatricians and orthopedic surgeons who do not understand or perform the treatment of Mehta/EDF casting.

(It’s sometimes still referred to as Risser Casting in hospitals, which is not the same thing.)

We love doctors and surgeons and we certainly need them. Most of the best casting doctors are also brilliant surgeons.

We do not disparage or even name doctors on our Facebook group. However, some medical professionals have unintentionally misled parents in the past and/or did not fully inform them of the severity and urgency of the progressive form of this condition.

To be clear, this is considered the only potentially life threatening condition in pediatric orthopedics and is the most difficult orthopedic condition to treat, so time is vital.

Our goal is simply the best treatment and quality of life for each precious scoli child.

Casting is challenging, but the surgery route begun young is not an easy path. There have been advancements in “distraction hardware”, but there are still many potential complications down the road.

With rapidly progressing cases of scoliosis, there is no time to waste, so I’ll be frank.

For casting to help optimally, acting fast is vital, ideally beginning casting under age 2 and under 50 degrees.

If your child has a curve with **a Cobb angle above 25 and an RVAD (rib vertebral angle degree) above 20, the scoliosis is considered progressive.**

The RVAD is a measuring technique developed by Dr. Mehta that will determine if the child’s scoliosis is of the progressive nature or not.

If the RVAD is over 20, it’s considered progressive, under 20 is considered self-resolving. Please discuss your child’s RVAD with the pediatric orthopedic surgeon.

In some cases, it can be a matter of a few months that make a huge difference in the treatment time and outcome. It’s important to advocate for your child. Be “politely pushy” if necessary.

Gather your information and make the appointments such as an MRI, if needed, and the first meeting with a casting doctor ASAP.

It’s generally a good idea to “get your ducks in a row,” just to be safe. If your child self resolves, you can always cancel medical appointments later, but it can take time to get in.

You may need to consider travel to get to see a Mehta trained doctor, but you can first often get early information and an opinion by mailing or emailing respected casting doctors these things:

Your child's X-rays, photos of their back and sweet face, as it's nice to put a face to a name, and your short medical story so far (a one page letter/email or less is fine).

Through Shriner's Hospitals, you can often contact the doctor through the Care Coordinator. Ask the group, without using doctor's names, to privately message you or email you the contact info for your hospital of choice.

What you want **is the most experienced Mehta/EDF casting doctor near you.**

Your child will likely need an MRI of their spine and possibly both brain and spine to rule out things like tethered cord syndrome or Chiari Malformation before casting.

In some cities, there can be a wait for this, even months to schedule at the best hospitals. I suggest just setting up the appointment with the casting doctor and the MRI Neurologist as fast as you can if your child's curve is high (over 20-25 degrees) and is progressive.

Not all casts are created equal.

This procedure must be done on an EDF casting frame and the young patient must be anesthetized for optimal results. The child's spine, muscles, ligaments must be relaxed for the surgeon to properly derotate the young patients spine, which is KEY for full correction.

Anesthetizing the patient also eliminates trauma related to being awake on the casting frame with strangers poking and prodding. A proper

Mehta Cast cannot be done without anesthetizing the patient or without having the proper EDF casting frame.

According to Dr. Mehta, over the shoulder casts are the best to address all curve types, especially with an apex (highest curve point) of T-8 and above.

That said, many children have been helped and/or cured by under the shoulder casts, too, you just want the best cast for your child.

Also ask your doctor if they are willing to “go the distance” with casting. Some surgeons will only apply, say 2-3 casts, before transferring to a brace, even if the curve is still high. This approach is not Mehta casting.

The goal of Mehta Casting is to cast until the patients curves are 10-20 degrees or below. The key to full correction is to correct rotation and reduce Cobb angle to its lowest possible degree.

The lower the curves are decreased gives the spine, muscles, tissues and ligaments the best chance at growing straight, permanently. This may take 3 casts or it may take 15 casts, depending on the severity of the child’s scoliosis.

If it is a more “surgery focused” practice and the surgeon is not willing to apply a year or more of casting (which is sometimes needed), then they may be the kind of surgeon that applies a "cookie cutter," approach to casting for all of their young patients and then ultimately opts to perform surgery.

After 2-3 casts, if they see minimal to no correction, they may stop casting, which is unfortunate, because many young children can achieve correction with a longer series of casts.

Our children’s spines are unique and their treatment plan should be developed according to their individual presentation of scoliosis.

Moderate to severe curves will likely need more than 2-3 casts, and if that is the case with your child, you will need an experienced surgeon that is willing to go the distance with your child’s series of Mehta Casts.

Slow and steady wins the race.

That said, surgery can be inevitable, by no fault of anyone, but you at least want to be sure your baby has the best chance at a non-surgical cure.

Our founder Heather’s beautiful, brave daughter Olivia died after multiple surgeries that caused premature fusion of her spine, a rigid chest wall and complications from having the chest cavity the size of a 7 yr. old.

Olivia was on oxygen by age 16 and a ventilator would have been in her future because she didn’t get the casting treatment in time to spare her and her mother so much unfair and terrible pain.

This is why Heather is a passionate advocate that this not happen to another child and it’s why I’m writing this now, because Heather saved my son from that same story.

Mehta casting is far harder on the parents than on the casted kids, that is the overall experience we have seen time and again. Your child will amaze you. Our warrior scoli kids are incredibly resilient.

Casting is temporary and removable. Once the surgery route has begun, there is no turning back. Casting is challenging, but it is do-able.

There are kids who have been cured or had their curves reduced well out of surgery range that began at 60, even 80 or more degrees.

Our son was at 64 degrees at 19 months of age in a standing X-ray (which is most accurate when possible, and usually a higher number than lying down.)

Many children who are older than two are cured or gain valuable growing time with casting prior to surgery. Severe cases sometimes also benefit from halo traction.

Generally, the lower number you begin at (the COBB Angle or main curve number) and the younger you start; the less casting treatment is needed. Although again, each child is unique.

It is common to plateau or get “stuck” in the middle of casting, where it appears the numbers are not improving. We are grateful we stayed the course for 10 casts, but we would have needed many less casts if we had better advice earlier on.

As long as you are confident that you trust your casting doctor, going the distance and not giving up early can make all of the difference in the treatment outcome of progressive infantile cases.

That said: A properly applied cast should never be painful.

There are reasons casting cannot work for some kids, such as kids with some additional syndromes or skin breakdown. Skin breakdown is not common, but it can happen, so do take sores seriously.

Growing rod surgeries, even the newest innovations, can still only be lengthened about 5-6 times, every six months.

If the rod surgeries are begun very young, your child may not grow to full height and not only experience deformity and pain, but potentially serious future pulmonary (lung) problems and other complications.

Our hospital told us these surgeries have more than a 100% complication rate, so surgery should be a last resort.

This is partially because our lungs are genetically programmed to grow to full adult size, even if the chest wall is shortened by hardware distraction surgeries.

We are now seeing that some young spines prematurely fuse themselves with growing rods inserted after only a few years, which defeats the entire purpose of distraction hardware.

This is another reason Mehta casting is a valuable tool to buy precious growth time. Please discuss this possibility with your child's treating surgeon prior to taking the surgery route.

No one is blaming any parents whose child requires surgery; we will all do whatever is the very best option for our children at any time and we support each other.

Some of the most spectacular parents we have in our group have precious children who needed surgery eventually, including our founder's angel Liv. We are all in this together. You simply deserve to know all of the information available to make your own deeply personal, informed decisions.

Some of us were unintentionally misled early on by very respected doctors, and it’s upsetting that it still happens years later. It may have been simply lack of knowledge and there were no ill intentions, but we have more parent information, now.

There are now several American published studies on Mehta’s Growth Guidance Casting, which we didn’t have years ago as proof of its effectiveness.

Some doctors even have their own money invested in the hardware they implant into children’s spines. The installation and repeated lengthening surgeries with all associated complications can make approximately 1 million dollars per child over a lifetime, if not more.

You have a right to know the facts and your non-surgical options.

All of that being said, you are in the right place and you are doing the right thing researching and advocating for your baby.

Other parents, grandparents and caregivers have walked this road before you and <u>you are not alone</u>.

EOS is a very emotional diagnosis and experience and can be traumatizing for parents and caregivers, so please take care of yourself and get all of the support you need.

But, take heart; we see success stories all of the time on our group.

That is thanks to our angel Olivia, Dr. Mehta, Heather Hyatt Montoya, the dedicated doctors who are saving our children’s spines every week, and parents like you who help spread the word on Mehta's Growth Guidance Casting.

You CAN do this! And you can help save the next child too, by being a part of our support group, spreading the word and maybe someday sharing your child's story.

We reach back a hand and lift the next family up; it's one of the precious gifts of grace we find on this crooked path.

It may be hard to believe this now, but there's so much beauty along the way. This is a beautiful and painful road, it's painful, but it's worth every single moment.

With much love on your journey, you are already a scoli warrior and our brave children are superheroes.

Onward,

~ Heidi (Bexon's Mama)