

Who is IMDSA?

International Mosaic Down Syndrome Association is a nonprofit organization designed to provide support, information, and research to anyone touched by mosaic Down syndrome.



What does IMDSA have to offer?

- ◆ Information packet full of MDS information, research, and inspirations
- ◆ Multi-language Brochures for families and professionals
- ◆ Quarterly newsletter *MOSAIC WORLD* packed with MDS news, tips, information and stories
- ◆ Biennial Research & Awareness Conference
- ◆ Awareness Jewelry and Ribbons
- ◆ Family Connect program
- ◆ Research Connect program
- ◆ Online support groups for families of all ages
- ◆ Toll Free Hotline for information and support
- ◆ Informative website to stay up-to-date with IMDSA

How can I become a member or donate to IMDSA?



CONTACT US!

IMDSA
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Franklin, Texas 77856
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PH: 1-979-828-4177
1-888-MDS-LINK
Fax: 1-775-295-9373
www.imdsa.org



Uniting Unique People in a Unique World

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Franklin, Texas 77856
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*"Your dreams for your child are not dead,
just taking a different path."*



We realize that when your child is diagnosed with mosaic Down syndrome you have many questions and may be worried about what this means for you and your child's future. We hope that the information you find here will help answer some of those questions you have right now.

The first thing we want to tell you is that you are not alone!

We have found that the best way of support is through others who have lived what you are living. Families can help you put your feelings and concerns into perspective and can provide you with a wealth of information. You can meet with these families through our online support groups which are found through our website www.imdsa.org.

or contact us to see if there is someone living in your area.

Almost everyone goes through a grief process after discovering their child has a disability. Many feel scared, alone, sad, angry, worried, or even relieved that finally they have a name for their child's difficulties. These feelings are normal, and everyone expresses their feelings in a different way. If you feel overly depressed or depressed for more than a couple of months, you should speak with a counselor about your feelings. They are there to help you.



What is mosaic Down syndrome?

When a person has mosaic Down syndrome a percentage of their cells have three copies of chromosome 21 (instead of the typical two copies) and the remaining cells are unaffected. Sometimes, the extra cells can be only in the blood or only in the skin, but most of the time cells are found in both skin and blood. Approximately 3% of the Down syndrome community are diagnosed with mosaic Down syndrome.

What did I do to cause my child to have MDS?

Nothing at all! Mosaic Down syndrome happens during cell division during or right after conception. It happens in every race, religion, and country. You did nothing to cause this to happen.

My child does not look like s/he has Ds.

Will s/he be higher functioning?

The old saying "You can't judge a book by its cover" rings true here. You can not determine your child's abilities by the Down syndrome characteristics they present. Where the extra cells are located in the body will determine how your child is affected. The majority of people with MDS develop at a faster rate than those with Ds. Some do not experience any developmental delays while others have extreme delays in one or more areas.



Will my child need extra help?

The majority of children with MDS require Early Intervention. Your child may have developmental delays with speech, and fine and gross motor skills. With the help of Speech, Occupational, and Physical Therapists, your child's delays can be helped and often s/he will overcome these delays. Some children require special education once they reach school age. Most children are "mainstreamed" in regular education classrooms, leaving for extra support in academic areas. However, some children with MDS require no special education at all!

What health concerns should I know about?

People with MDS can have the same health concerns as a person with Ds. It is important to talk with your doctor about having scheduled Down syndrome health check-ups as described by the DSMIG.

What does the future hold for my child?

No one can tell you what your child will grow up to be! People with mosaic Down syndrome can grow up to be great adults!

"He may go to college, he may not. He may get married, he may not. She may have children, she may not. Her children may have Down syndrome, they may not."

People with MDS have the same feelings as anyone else and the same ambitions as their peers.

How should I treat my child with mosaic Down syndrome?

Expect the very best from your child and your child will give you their very best! Give them the love and attention that every child needs and enjoy them for who they are. Mosaic Down syndrome is not *WHO* your child is - it is *WHAT* your child has.



The Only Handicap A Person Has Is The People Around Them!

How am I going to tell my family and friends?

Telling your family and close friends can sometimes be hard, and each person handles things differently. Your family and close friends can offer you and your child support. And, sometimes not telling them is harder than telling them. You don't have to tell everyone, and it is ok to choose who you tell this information to.

"The first ones we told were our mothers, and in no way did it change their view of her, in fact I think they gave her 'extra' love ... they wanted her to know for sure she was loved!!"

How is this going to affect my other children?

Research has shown that siblings become more compassionate individuals due to having a brother or sister with a disability and often they become professionals in the medical or educational field.



"I really do not think about my brother having MDS. He is just like anyone else and I don't see him any differently."