

Support

Finding out that you or a family member has a rare genetic disease such as TTR amyloidosis can be worrying and challenging, both physically and emotionally. You are not alone, and you and your family should speak to your physician about any concerns you may have.

Your physician can also provide information about genetic counseling if you are concerned for yourself following the diagnosis of a family member or for members of your family if you have been diagnosed with TTR amyloidosis.

There are a number of patient groups who can also provide support and information:

Australia

Amyloidosis Australia www.amyloidosis.com.au

Brazil

Associação Brasileira de Paramiloidose www.abpar.org.br

Canada

The Canadian Amyloidosis Support Network, Inc. www.thecasn.org

Italy

La Società Italiana per l'Amiloidosi www.amiloidosi.it

The Netherlands

Groningen Unit for Amyloidosis Research & Development (GUARD) www.amyloid.nl

Portugal

Associação Portuguesa de Paramiloidose www.paramiloidose.com

Switzerland

Amyloidose PWAS www.amyloidose.ch

United Kingdom

National Amyloidosis Centre www.ucl.ac.uk/medicine/amyloidosis/nac

United States

Amyloidosis Foundation www.amyloidosisresearchfoundation.org

Amyloidosis Support Groups www.amyloidosisissupport.com

Amyloidosis Support Network www.amyloidosisissupportnetwork.org

National Organization for Rare Disorders, Inc. www.rarediseases.org

The Rare Disease Community www.inspire.com/groups/rare-disease