List of resources

This document lists useful resources, including guidelines, reports, and links that may be useful to people interested in setting up an amyloidosis center.

Guidelines, position statements, and expert consensus papers

- **Moving towards establishing centers of excellence in cardiac amyloidosis: an International Cardio-Oncology Society statement**
  Position statement which outlines the elements necessary for highly effective clinical care and develops a general standard with which practices or institutions could be recognized as a center of excellence for amyloidosis.
- **Guidelines and new directions in the therapy and monitoring of ATTRv amyloidosis**
  Guidance on treatment and monitoring disease progression and treatment efficacy from the International Society of Amyloidosis (ISA) ATTR Amyloidosis Working Group.
- **Diagnosis and treatment of cardiac amyloidosis: a position statement of the ESC Working Group on Myocardial and Pericardial Diseases**
  Guidance from the European Society of Cardiology (ESC) on the diagnosis and management of cardiac amyloidosis, by the Working Group on Myocardial and Pericardial Diseases.
- **World Heart Federation consensus on transthyretin amyloidosis cardiomyopathy (ATTR-CM)**
  Comprehensive guidelines and recommendations for the diagnosis, management, and treatment of cardiac amyloidosis due to transthyretin amyloid deposition, with an emphasis on the importance of a multidisciplinary approach and specialized amyloidosis centers.
- **Consensus recommendations on holistic care in hereditary ATTR amyloidosis: an international Delphi survey of patient advocates and multidisciplinary healthcare professionals**
  Consensus recommendations on holistic care for hereditary ATTR amyloidosis, derived from an international Delphi survey involving patient advocates and multidisciplinary healthcare professionals.
- **Systemic light chain amyloidosis, version 2.2023, NCCN Clinical Practice Guidelines in Oncology**
  The NCCN Guidelines for workup, diagnosis, and treatment of primary and previously-treated systemic light chain amyloidosis.
- **Expert consensus recommendations to improve diagnosis of ATTR amyloidosis with polyneuropathy**
  Collaborative recommendations from experts to improve the diagnosis of hereditary transthyretin amyloidosis with polyneuropathy.
- **JCS 2020 guideline on diagnosis and treatment of cardiac amyloidosis**
  Guidelines from the Japanese Circulation Society (JCS) offering recommendations for diagnosing and treating cardiac amyloidosis.
- **Diagnosis and management of transthyretin familial amyloid polyneuropathy in Japan: red-flag symptom clusters and treatment algorithm**
  Recommendations from Japan on diagnosing and managing transthyretin familial amyloid polyneuropathy, including symptom clusters and treatment algorithms.
- **Chinese consensus on the diagnosis and treatment of immunoglobulin light-chain cardiac amyloidosis**
  Consensus recommendations from China on diagnosing and treating immunoglobulin light-chain cardiac amyloidosis.
- **Clinical recommendations to diagnose and monitor patients with transthyretin amyloid cardiomyopathy in Asia**
  Recommendations tailored to Asia for diagnosing and monitoring patients with transthyretin amyloid cardiomyopathy.
- **2023 expert consensus of the Taiwan Society of Cardiology on the diagnosis and treatment of cardiac amyloidosis**
  Expert consensus from the Taiwan Society of Cardiology Heart Failure Committee on the diagnosis and treatment of cardiac amyloidosis.
- **Guidelines and new directions in the therapy and monitoring of ATTRv amyloidosis**
  Covers guidelines and emerging therapeutic directions for hereditary transthyretin amyloidosis.
- **Guidelines for high dose chemotherapy and stem cell transplantation for systemic AL amyloidosis: EHA-ISA working group guidelines**
  Guidelines developed by the stem cell transplant working group of the International Society of Amyloidosis (ISA) and European Haematology Association (EHA).

Publications from existing amyloidosis centers

- **The UK National Amyloidosis Centre: The National Amyloidosis Centre at the Royal Free Hospital and University College London is the world's largest amyloidosis center with almost 1500 patient referrals annually**
  This paper describes the United Kingdom (UK) National Amyloidosis Centre located at the Royal Free Hospital and University College London, highlighting its status as the world's largest amyloidosis center.
- **Establishment of a diagnostic center for amyloidosis in Japan by Kumamoto University**
  This publication briefly discusses the current operations of a national amyloidosis center in Japan and the characteristics of patients presenting to this diagnostic center.
- **Transthyretin amyloidosis: testing strategies and model for center of excellence support**
  Publication describing experience in establishing a center of excellence in Sofia, Bulgaria and defining the fundamental steps needed to successfully launch a program.

AstraZeneca has provided an educational grant towards this independent program.

- **Extending the reach of expert amyloidosis care: a feasibility study exploring the staged implementation of a UK amyloidosis network**
  This paper investigates the feasibility of expanding expert amyloidosis care through a staged implementation of a UK amyloidosis network, highlighting strategies to enhance collaboration, accessibility, and quality of care across different healthcare settings.
- **Multidisciplinary amyloidosis care in the era of personalized medicine**
  This publication discusses the importance of a multidisciplinary comprehensive amyloidosis clinic, drawing on experience at The Ohio State University, USA as an example.
- **Optimal practices for the management of hereditary transthyretin amyloidosis: real-world experience from Japan, Brazil, and Portugal**
  Summary of best practices in amyloidosis centers in three major endemic countries for ATTRv amyloidosis, including Japan, Brazil, and Portugal.
- **Best practices in specialized amyloidosis centers in the United States: a survey of cardiologists, nurses, patients, and patient advocates**
  Paper investigating best practices in specialized amyloidosis centers in the United States through a survey involving cardiologists, nurses, patients, and patient advocates.

Publications about starting an amyloidosis program

- **Comprehensive approach to cardiac amyloidosis care: considerations in starting an amyloidosis program**
  Considerations and suggested steps in starting and expanding an amyloidosis program.
- **Establishing a cardiac amyloidosis clinic: a practical primer for cardiologists**
  Discussion points and key recommendations for the development of a cardiac amyloidosis clinic from a meeting of specialists in Canada.

Networks

- **European Reference Networks (ERN)**
  ERNs are virtual networks involving healthcare providers across Europe. Their goal is to facilitate discussion on complex or rare diseases and conditions that require highly specialized treatment, and concentrated knowledge and resources.
- **RN-EuroBloodNet**
  RN-EuroBloodNet is a collaborative network aiming to improve the healthcare services of complex or rare hematological diseases and conditions that require highly specialized treatment in Europe.
- **ERN EURO-NMD**
  Network of healthcare centers that work to speed up diagnosis and research in rare neuromuscular diseases and improve the standards of care for these pathologies.
- **ERN GUARD-Heart**
  The mission of ERN GUARD-Heart is to facilitate access to highly specialized diagnosis and treatment of rare and complex heart diseases in both adult and pediatric patients across the European Union.
- **ORPHANET**
  Orphanet is a unique resource, gathering and improving knowledge on rare diseases to improve diagnosis, care, and treatment of people with rare diseases.

Societies

- **International Society of Amyloidosis (ISA)**
  The ISA is a non-profit organization of scientists and physicians engaged in research, teaching, or practice in connection with amyloid and amyloidosis.
- **The German Society of Amyloid Diseases**
  Supports physicians and scientists researching the causes and consequences of amyloidosis and promotes efforts to improve the understanding and treatment of amyloidosis.
- **Italian Society for Amyloidosis (SIA)**
  The SIA aims to support initiatives aimed at spreading knowledge of amyloidosis among doctors to facilitate early diagnosis and to promote scientific research in the field of primary or light chain (AL) amyloidosis.
- **Japanese Society of Amyloidosis (JSA)**
  The JSA is a professional organization dedicated to advancing research, education, and clinical care related to amyloidosis in Japan.

Advocacy groups and patient organizations

Amyloidosis Foundation
Location: International

Amyloidosis Alliance
Location: International

Amyloidosis Research Consortium
Location: International

Amyloidosis UK
Location: United Kingdom

FAP eV
Location: Germany

Association Française Contre l'Amylose
Location: France

Associação Portuguesa de Paramiloidose
Location: Portugal

Amyloïdose Nederland
Location: The Netherlands

The Associazione Italiana Amiloidosi Familiare Onlus (FAMY)
Location: Italy

FaMY Norbotten
Location: Sweden

Amyloidosis Ireland
Location: Ireland

Leben mit Amyloidose
Location: Austria

Hereditary Amyloidose Hwanwoohoe
Location: South Korea

Asociación Española de Amiloidosis
Location: Spain

ABEA
Location: Spain – Balearic Islands

ASVEA
Location: Spain

Amyloidosis Support Groups
Location: USA

Amyloidosis Speakers Bureau
Location: USA

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