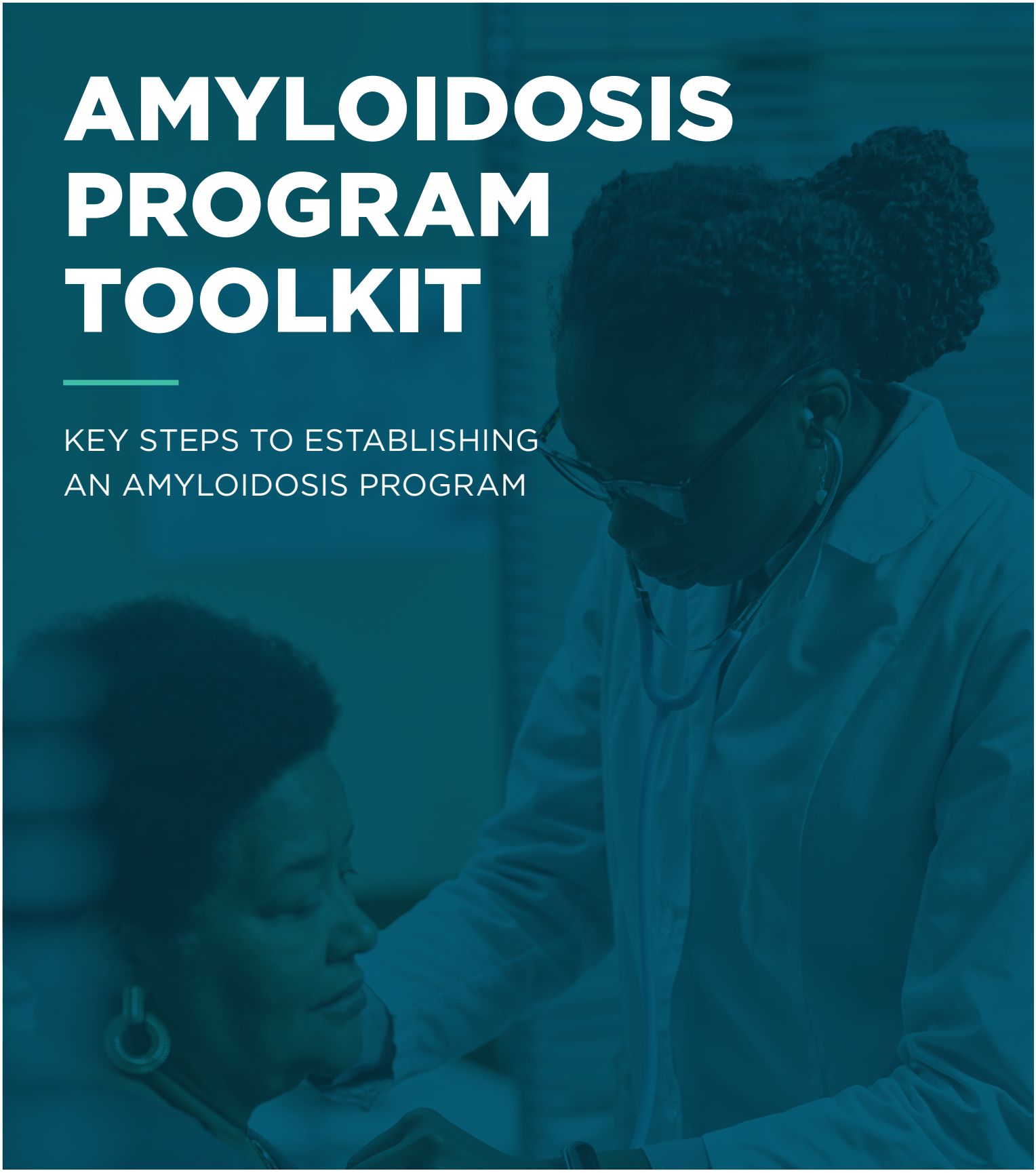
AMYLOIDOSIS PROGRAM TOOLKIT

KEY STEPS TO ESTABLISHING AN AMYLOIDOSIS PROGRAM



Amyloidosis Research Consortium

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Whether you're launching a new program or strengthening an existing one, these recommendations can help more patients receive timely, expert care.

Building an amyloidosis program takes more than clinical expertise. It takes coordination across specialties, reliable diagnostics, institutional buy-in, and strong connections to the broader amyloidosis community.

This toolkit is a practical guide for clinicians and program leaders who want to start or expand an amyloidosis center. It walks through the core building blocks, from identifying internal partners to engaging hospital leadership. Each section points to resources that can support your work.

KEY RESOURCE REQUIREMENTS

I. Internal Partners

Amyloidosis care is multidisciplinary by nature. No single specialty can manage it well alone. The first step in building a program is mapping out who inside your institution will be part of the team, starting with the essentials and adding depth as resources allow.

MINIMUM REQUIREMENTS

- Cardiology
- Hematology/Oncology
- Neurology
- Radiology/Nuclear Cardiology

MORE COMPREHENSIVE PROGRAM

- Cardiology, including heart failure, transplant services, electrophysiology, and structural heart
- Hematology/Oncology
- Radiology and Nuclear Cardiology
- Neurology
- Nephrology
- Gastroenterology
- Orthopedics
- Genetic Counseling
- Specialty pharmacy with 340B program access
- Social Work

II. Staffing & Clinical Support

Physicians alone can't sustain an amyloidosis program. Patients need ongoing education, coordination, and follow-up testing that nurses and advanced practice providers are well positioned to deliver. The right support staff is often the difference between a program that scales and one that burns out its clinicians.

Advanced practice providers (NPs and PAs) to support patient visits, education, follow-up testing, and care coordination

Nursing support to assist with patient visits, education, follow-up testing, and care coordination

A defined plan for recruiting and retaining these roles as the program grows

III. Patient Screening

Most amyloidosis cases are missed because signs and symptoms were missed or misdiagnosed. Building screening into existing clinical workflows, from heart failure and EP clinics to orthopedic referrals, is how programs shift from reactive to proactive diagnosis.

Screen at risk populations: HFpEF, HFrEF, atrial fibrillation, and aortic stenosis

HF and cardiology clinics, EP clinics, inpatient HF and cardiology service. Partner with internal medicine and family medicine residencies

Coordinate with the structural heart team on TAVR evaluations

Work with orthopedic colleagues to send surgical specimens for pathology review, enabling earlier identification of extra-cardiac disease

Explore AI-based tools to support screening and diagnostic decision-making

IV. Diagnostics

Accurate diagnosis is the foundation of everything that follows. Amyloidosis subtyping drives treatment choice. A strong program needs reliable access to the right labs, imaging, and biopsy capabilities, along with the expertise to interpret them.

Labs: SPEP/UPEP with immunofixation and cardiac biomarkers (NT-ProBNP or BNP and troponin)

PYP/HDP/DPD: need to ensure proper protocols are followed including SPECT/CT

Echo: ability to perform good quality echo, strain imaging may be helpful

MRI: ability to perform cardiac MRI, including LGE and ECV

Order sets may be helpful to standardize workup approach

Ability to perform and interpret biopsy (endomyocardial, fat pad, bone marrow). Ability to send the specimen for confirmation with Mass Spect.

Genetic testing:

- Sponsored genetic testing provided by Prevention Genetics through partnership with Alnylam and AstraZeneca
- TTR only gene vs comprehensive cardiomyopathy or comprehensive neurology panel

V. Patient Resources & Education

Patients absorb a lot at diagnosis, and most of it doesn't stick the first time. Good programs connect patients with educational materials, support communities, and peer networks so they can learn at their own pace and feel less alone on the journey.

Contact amyloidosis patient advocacy groups such as the **Amyloidosis Research Consortium**, **Amyloidosis Support Groups**, **Amyloidosis Foundation**, and **Mackenzie's Mission** for information on a range of educational materials, resources and support opportunities for your patients. Reach out to **support@arci.org** for more details.

Pharmaceutical companies can also offer assistance for patient resources, nursing support and education information. Reach out to your local MSL or salesperson for more information.

INSTITUTIONAL RESOURCE ASSESSMENT

Before committing to a program scope, take honest stock of what your institution is equipped for. Identify what kind of resources are available at your institution.

- Can your institution screen at-risk patients effectively?
- Can it complete the full diagnostic workup, including labs, PYP imaging, and biopsy (endomyocardial, fat pad, bone marrow)?
- Can it prescribe disease-modifying therapies for ATTR and chemotherapy regimens for AL amyloidosis?
- Does it offer advanced therapies such as heart transplant, stem cell transplant, or second-line anti-plasma cell therapies?
- Does it provide access to ongoing clinical trials for ATTR and AL amyloidosis?

EXTERNAL PARTNERSHIPS

Few programs can do everything. Thoughtful partnerships with other centers expand what you can offer patients, from advanced therapies to clinical trials, without requiring your institution to build every capability from scratch. Depending on the expertise and resources available at your institution may need to partner with other centers.

- If internal resources are limited, partner with established centers that provide advanced therapies and second opinions.
- If your program has strong core capabilities, partner with surrounding clinics and centers to expand patient access.
- If you are in the early stages, build relationships with experienced centers for case consultation, second opinions, and clinical trial access.
- Consider your institutional structure. Are you a standalone hospital or part of a larger health system? There might be good opportunities for partnering with other centers. A hub-and-spoke model can support regional coordination and referral pathways, for example.

LEADERSHIP ENGAGEMENT

A program lives or dies by the support it gets from institutional leadership. Making a clear case for why amyloidosis care matters, both clinically and financially, is how programs secure the resources they need to grow. Engage with your program leadership to:

- Articulate the unmet need, including the number of patients likely missing diagnoses at your institution and the missed opportunities to initiate disease-modifying therapies.
- Build a long-term program growth and sustainability plan covering the patient care and diagnostic testing the program supports, and benefits of participation in specialty pharmacy and 340B programs.
- Define the resources required to deliver on the plan, including staffing, equipment, and infrastructure.
- Establish clear benchmarks for success and a timeline for reassessing progress.

ADDITIONAL RESOURCES

The field is moving quickly. The publications below offer deeper guidance on program development, supportive care, and current treatment standards.

APPROACH TO MULTIDISCIPLINARY PROGRAM DEVELOPMENT

- **ISA Position statement**: Sanchorawala V, et al; Amyloid. 2025; 32 (4): 303-308
- **International Cardio-Oncology Society Statement**: Cheng R, et al; Heart. 2024; 110: 823-830
- **Comprehensive approach to cardiac amyloidosis care**: considerations in starting an amyloidosis program: Sperry BW, et al; Heart Fail Rev. 2022; 27(5): 1559-1565
- **Establishing a Cardiac Amyloidosis Clinic**: A Practical Primer for Cardiologists: Davis MK, et al; Can J Cardiol. 2021; 37(4): 674-678

SUPPORTIVE CARE AND TREATMENT REFERENCES

- ISA: **Supportive care for systemic amyloidosis**: Muchtar E, et al; Amyloid. 2025; 32(2): 93-116
- **ACC Concise Clinical Guidelines**: Kittleson MM, et al; JACC. 2025
- **Heart Transplantation**: Mayo Clinic Consensus Statement: Lyle MA, et al; Mayo Clinic Proceedings. 2025; 100(9): 1578-1605
- **Frailty. State of the Art Review**: Bart N, et al; JACC: Advances. 2025; 4(6): 1-22.
- **Treatment of AL Amyloidosis**: mSMART, Consensus Statement 2020 Update. Mayo Clin Proc. 2021; 96 (6): 1546-1577

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