



2021 LEAD Capstone Poster Session

UT Southwestern Multidisciplinary Amyloidosis Program

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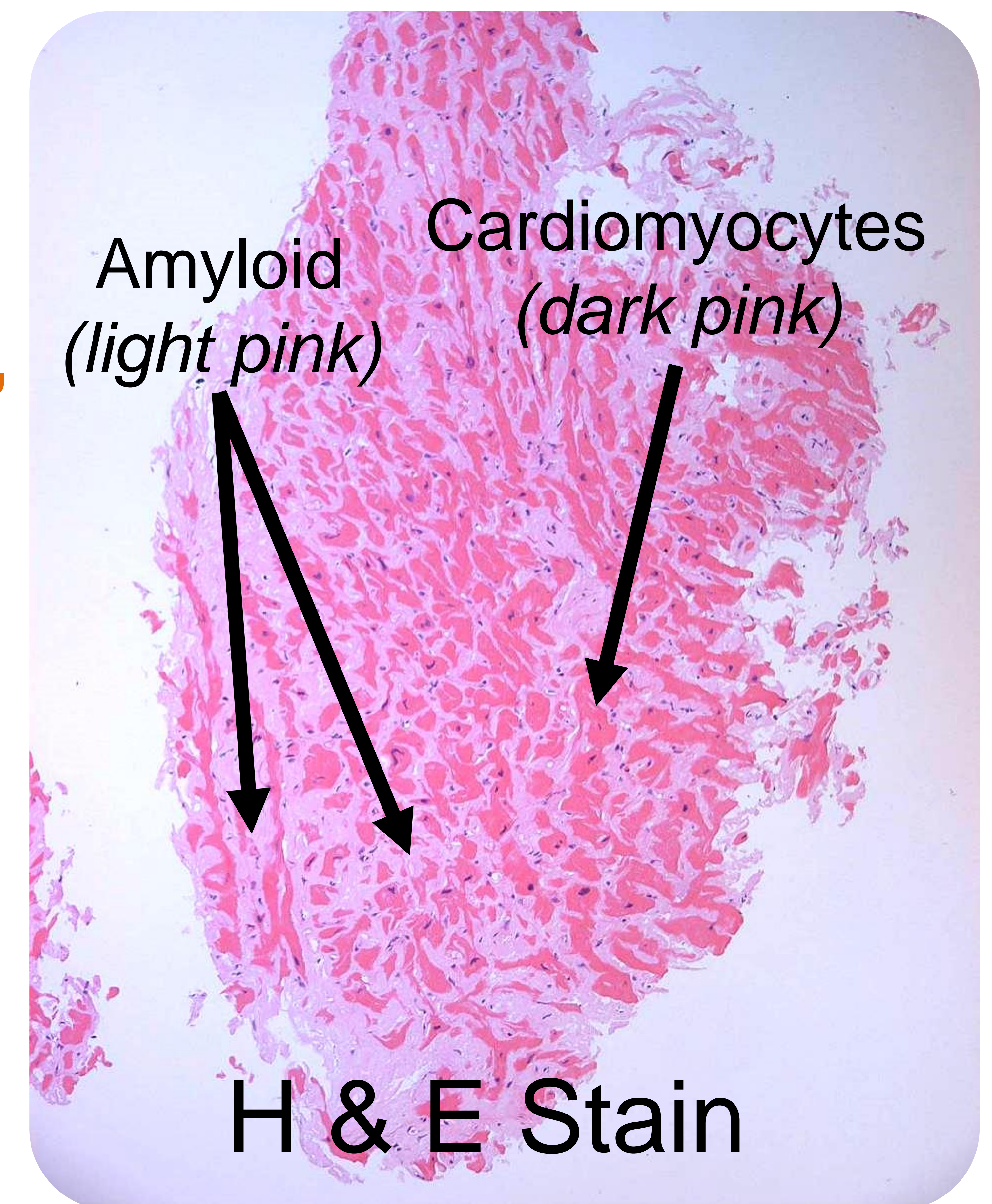
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Abstract

- **Background.** Amyloidosis all too often “slips through the cracks” and goes undiagnosed.
- Amyloidosis is caused by the abnormal build-up of protein that causes organ dysfunction.
 - These organs can include the heart, kidneys, nerves, and GI tract.
- Untreated, this disease leads to suffering and premature death.
- Few centers in the USA provide a multidisciplinary approach to the diagnosis, treatment, and care of patients with amyloidosis.

Right Ventricle Biopsy





Abstract

- **Objective.** To establish the UT Southwestern Multidisciplinary Amyloidosis Program (UTSW MAP).
- **Methods.** Establish a team that offers comprehensive, state-of-the-art amyloidosis care, delivers cutting edge clinical and translational research, and is a leader in amyloidosis patient advocacy.
- **Outcomes.**
 - Improve clinical care for patients with amyloidosis
 - Establish UTSW as a leader in amyloidosis clinical care and research
 - Heightened referral volumes to UTSW
 - ✦ Leads to “halo effect”
 - Unique education opportunities for trainees



Objectives

- Establish a multidisciplinary team of amyloidosis with expertise across a range of disciplines to efficiently and effectively deliver comprehensive amyloidosis care.
- Establish a rich, clinical and translational amyloidosis research program.
- Establish UTSW as a leading institution for amyloidosis patient advocacy



Background Information

- UTSW MAP formed in 2018
 - Cardiology, Hematology/Oncology, Neurology, Geriatrics, Hepatology, Gastroenterology, PM&R, Nephrology, Pathology, and Psychology
- Clinical / Translational research
 - 4 clinical trials testing novel amyloid therapeutics
 - ✦ Eplontersen, acoramidis, and CAEL-101
 - **Saelices Lab**: developing inhibitors of amyloid aggregation
 - Registry studies, epidemiology, and biobanking
- Patient Advocacy

This growth has created a crucial unmet need for further RN and research support and marketing resources



Specific Aims

- To establish a multidisciplinary team of amyloidosis experts to deliver efficient, coordinated, state-of-the-art amyloidosis care
- To deliver cutting-edge clinic and translational research
 - Sub-aim. To establish the UTSW Amyloidosis Biobank
- To establish UTSW as a leader in amyloidosis patient advocacy



Project Plan

- Establish monthly UTSW MAP meetings
- Establish an amyloid nursing triage unit
- Broaden access for established patients
- Expand resources for team-work and sub-specialization
- Develop patient education resources and care-coordination
- Lessen the burden of prior-authorizations
- Expand internal and external marketing efforts



Application of What You Learned at LEAD

- **Communication and Influence**
 - Identifying the attributes of effective, impactful communication
 - Establishing a brand and executive presence
- **Working as a Team**
 - Implementation of vetted business and leadership tools
 - Management of team diversity
 - Understand influences on collective decision making
- **Institutional knowledge**
 - Linking to UTSW strategic plan and identifying priorities of alignment



Proposed Budget

- Clinical Coordinator (RN)
 - FTE – 1.0, Annual Salary ~\$105,000.00
- Research Nurse (RN)
 - FTE – 1.0, Salary ~\$85,000.00 (seed fund)
 - ✦ *FTE is expected be grant funded from research beyond the initial seed funds*
- *Marketing Resources*
- *Multidisciplinary Amyloidosis Clinic (future)*



Innovation and Significance

- This project will be significant because it will establish UTSW as a leader in:
 - Clinical care for amyloidosis
 - Developing amyloidosis expertise for trainees
 - Clinical and translational research for amyloidosis
 - Advocacy for patients with amyloidosis
- This project will be innovative because it will:
 - Leverage and synergize expertise across disciplines as a model for multidisciplinary care
 - Identify UTSW as the only medical center in Texas that offers completely comprehensive amyloidosis care



References

- Griffin JM, Rosenthal JL, **Grodin JL**, Maurer MS, Grogan M, Cheng RK. ATTR Amyloidosis: Current and Emerging Management Strategies: JACC: CardioOncology State-of-the-Art Review. JACC CardioOncol. 2021;3(4):488-505. Epub 2021/11/04. doi: 10.1016/j.jaccao.2021.06.006. PubMed PMID: 34729521; PMCID: PMC8543085.
- Bianchi G, Zhang Y, Comenzo RL. AL Amyloidosis: Current Chemotherapy and Immune Therapy Treatment Strategies: JACC: CardioOncology State-of-the-Art Review. JACC CardioOncol. 2021;3(4):467-87. Epub 2021/11/04. doi: 10.1016/j.jaccao.2021.09.003. PubMed PMID: 34729520; PMCID: PMC8543128.