



### A message from the SCTC executive committee

We hope you have had a wonderful Summer. As the night's draw longer (for many of us at least), let us take the opportunity to bring you up to speed with recent efforts of the SCTC to support the needs of our community and patients. The SCTC has continued to develop and thrive with the addition of new members to the consortium. We have also received a further large legacy donation that will allow us to develop new initiatives to achieve our core missions.

We have continued to update our website and would encourage you to visit to keep updated on recent developments and forthcoming activities. We hope to see you in Atlanta for the forthcoming annual general meeting.

*Ariane, Lori Tracy & John*

### New Members

The SCTC continues to grow in numbers and stature.

We now have 131 member institutions and have been pleased to welcome the addition of 11 new member institutions to the consortium over the last 6 months:

Birmingham, UK (Dr Derrett-Smith)

Cambridge, UK (Dr Hall)

Grenoble, France (Dr Blaise)

Iasi, Romania (Dr Ancuta)

Madrid, Spain (Dr Carreira)

Mumbai, India (Dr Bhojani,)

Newcastle, UK (Dr Griffiths)

Nottingham, UK (Dr Lanyon)

Rennes, France (Dr Jego)

Santiago, Chile (Dr Valenzuela Vergara)

Sheffield, UK (Dr Akil)

### The White Paper Initiative

Peter Merkel and Dinesh Khanna are leading an initiative to draft a "White Paper" concerning outcomes in scleroderma that are acceptable to the FDA for use in RCTs.

This is a complex but critical area that the scleroderma research community needs to embrace to move the field forward. They have engaged partners from FDA and industry, have received an NIH R13 grant, have expert consultants on board, and are finalizing a set of Task Force members for the project.

The project will involve 6 Task Forces across six different domains and each group will be tasked with reviewing measures within their assigned domain and applying principles we will outline to determine whether the measures is fit for purpose according to FDA's mandate to measure how a patient feels, functions, or survives.

The initiative shall be discussed at the forthcoming AGM in Atlanta.

### Forthcoming SCTC AGM

This year's SCTC annual general meeting will be held on

**November 9th, 2019 at the Georgia State University Campus in Atlanta, Georgia.**

The main dinner and meeting will begin at 6:00 pm, and working group meetings will take place before and after the main meeting. An agenda will be sent out shortly.

This year, the SCTC is accepting nominations for the role of Vice-President. The SCTC is keen on global participation in order to improve international outreach, and therefore encourages anyone interested in joining the executive to enter their name for the running for the position of Vice President.

All nominees will be expected to submit a brief statement for circulation to the entire membership by October 11th, 2019.

Please send suggested nominations by September 30th 2019 to [sctcinc01@gmail.com](mailto:sctcinc01@gmail.com).

### A SCTC Working Group Update

The Scleroderma Clinical Trials Consortium Damage Index (SCTC-DI) is the culmination of five years of work by a dedicated international working group of the SCTC aided by non-rheumatologist experts and patient partners. Derived using a combination of consensus methodology and prospectively acquired data from a large Australian cohort, the SCTC-DI is comprised of 23 items, weighted according to the strength of association with health-related quality of life ('morbidity') and mortality. The SCTC-DI is intended for use as an outcome measure in observational and interventional studies. Other potential uses include enrichment of clinical trials for those with less damage who may be more likely to benefit from disease-modifying drugs. To date, the SCTC-DI has been retrospectively validated in a large Canadian cohort and prospective validation in an incident cohort is planned.

The development of the SCTC-DI has paved the way for the development of an Activity Index in SSc, a project that is currently in progress under direction of co-Chairs A/Prof Mandy Nikpour (Melbourne Australia) and Prof Murray Baron (Montreal Canada). Damage and Activity Index projects have been supported by grants from the SCTC.

Ferdowsi N, et al. Development and Validation of the Scleroderma Clinical Trials Consortium Damage Index (SCTC-DI): a novel instrument to quantify organ damage in systemic sclerosis. *Ann Rheum Dis* 2019. Jun;78(6):807-816.

### Other forthcoming meetings:

The 6th Systemic Sclerosis World Congress  
March 5th-7th 2020 in Prague

Abstract submission: Monday, September 23, 2019. Early bird registration fee: Monday, December 2, 2019

Further details available from: <https://web.aimgroupinternational.com/2020/sclerosiscongress/>