

A message from the SCTC executive committee

The SCTC has continued to develop and thrive in recent months with the addition of new members to the consortium, a large legacy donation, the development of new working groups and work on new initiatives such as the new bi-annual Newsletter.

We recognize the importance of keeping our members update on recent events, current initiatives and future plans. The SCTC shall produce and circulate a newsletter every Spring and Autumn to ensure you keep abreast of important developments within our thriving community. In this installment, we shall bring you news on a new funding stream made possible by a very generous legacy donation to our organization and shall encourage you to visit our updated website which shall be kept updated with additional work being undertaken by the team. We value your feedback on the website, newsletter and other initiatives that we are working on so please contact us with any suggestions for improvement.

Ariane, Lori Tracy & John

The Betty Benedict Donation

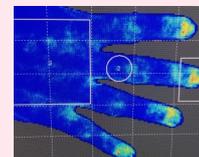
Betty Z. Benedict of New Jersey passed away on January 4, 2018 after a long struggle with systemic sclerosis. Her estate has gifted US\$1 million to the SCTC - its largest support ever. The Scleroderma Research Foundation of California received similar support. A graduate of Wellesley College, she was an analytical chemist at Merck & Co then pursued a second career as the Periodicals Librarian for Fairleigh Dickinson University. A tennis aficionado, she was renowned for her keen intellect, independence and kindness towards others.

Ms. Benedict developed systemic sclerosis later in life and received her care under Jim Seibold, a Founder and Past President of the SCTC, at Robert Wood Johnson Medical School in New Jersey. She was completely committed to the goals of the SCTC and recognized the key role of the organization in the ongoing quest to develop effective therapies. Her gift will support a major expansion of the research programs of the SCTC.

A SCTC and Scleroderma Research Foundation research scholarship in Ms. Benedict's name is being developed and further details regarding the award shall appear on our (new) website shortly.

A SCTC Working Group Update

The SCTC Vascular Working Group (VWG) was developed in 2015 to consider methods for assessing digital vasculopathy in scleroderma-related disorders.



SCTC seed-funding has enabled the VWG to work towards the development and validation of a novel patient-reported outcome (PRO) instrument for Raynaud's phenomenon. The new PRO shall be grounded in the patient experience of Raynaud's phenomenon in SSc and has been developed according to FDA and OMERACT principles for inclusion in future SSc-RP clinical trials. The Assessment of Scleroderma-associated Raynaud's Phenomenon (ASRAP) questionnaire is currently being validated in >500 patients from English-speaking centers based in the UK, US and Canada. We shall complete enrolment to the validation study by March 2020 and report preliminary findings from this work at the ACR meeting in 2020. The VWG is currently undertaking a similar program of work to develop a novel PRO instrument for the assessment of SSc-related digital ulcer disease.

Email JohnPauling@nhs.net for further information on supporting the activities of the SCTC -VWG

New SCTC Members

The SCTC continues to grow in numbers and stature. The SCTC is pleased to welcome the addition of 3 new sites to the consortium:

Dr Joanne Sahhar, Monash University, Melbourne, Australia

Dr Mislav Radic, Split, Croatia

Dr Lidia Rudnicka, Warsaw, Poland

In memoriam

The scleroderma community was shocked and saddened by the death of Dr. Nadia Morgan from the Johns Hopkins Division of Rheumatology. Dr Morgan received her MBBS degree at the University of the West Indies, completing her internship and residency training at SUNY Downstate Medical Center before moving to Baltimore. Dr. Morgan had an interest in ethnic disparities in the clinical presentation of rheumatic diseases, particularly as it pertains to pulmonary pathology in scleroderma, and was a leading investigator on the important GRASP programme of research.



The SCTC have pledged \$2500 towards a research scholarship planned in her honour.

New SCTC website

The SCTC have developed a new website and are grateful to Anne Chinoy from Kangablu for her efforts on this initiative. The website is much easier to navigate and will be useful for SCTC members and others to learn more about the mission of the SCTC, forthcoming grant award streams and other SCTC activities. Visit us at: <https://sclerodermaclinicaltrialsconsortium.org/>

Forthcoming meetings

The 16th International Scleroderma Workshop on Scleroderma Research shall be taking place on July 27th-31st 2019 in Cambridge, UK. The workshop continues to grow and is an important meeting in the scleroderma calendar. The SCTC shall be supporting the meeting with a dedicated session at the meeting (tbc). Please visit the following website for further details: <https://sscworkshop.wordpress.com>