

# Amsterdam, October 2<sup>nd</sup>: iSPIN: Combining Forces

*Combining forces to develop, test and disseminate eHealth interventions in rare diseases: the example of the Scleroderma Patient-centered Intervention Network (SPIN)*



Prof. Brett Thombs  
McGill University



Prof. Pim Cuijpers VU  
Amsterdam



Maureen Sauvé  
Scleroderma Society of  
Canada



Prof. A van Straten  
VU Amsterdam



Prof. Luc Mouthon  
Hospital Cochin



Joep Welling  
NVLE



Dr. Linda Kwakkenbos  
McGill University



Dr. W. van Ballegooijen  
VU Amsterdam

*Attendance is free, but your participation requires registration. Register by sending an email with your name and affiliation to [✉ combiningforces2015@gmail.com](mailto:combiningforces2015@gmail.com)*



# iSPIN: Combining Forces

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## **Preliminary Program:**

9:30-10:00 Registration / coffee and tea

10:00-12:30 **SPIN: overcoming barriers to non-pharmacological research in rare diseases**

- \* Challenges in rare disease research – Prof. Thombs
- \* Comprehensive care for scleroderma – Prof. Mouthon
- \* The cohort multiple RCT design – Dr. Kwakkenbos
- \* Patient involvement – Ms. Sauvé and Mr. Welling

## **eHealth interventions: creating opportunities**

- \* Introduction to eHealth interventions – Prof. Cuijpers
- \* Novel approaches in eHealth – Dr. van Ballegooijen

12:30-13:30 Lunch (included)

13:30-16:30 **Interactive Network Sessions** - Prof. Thombs, Prof. van Straten, Dr. Ruwaard, Dr. Kwakkenbos, Mr. Welling

16:30-18:00 Reception

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**Where: Aristo Amsterdam, Tempelhofstraat 2, 1043 EC  
Amsterdam, the Netherlands**



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Internationally, National Plans for Rare Diseases have emphasized the need for the development and delivery of programs that support patients and their families in coping with rare diseases. The National Plans emphasize the emotional, physical, and management challenges that people living with a rare disease face, and the dramatic lack of resources to support effective coping.

Effective strategies that are readily disseminated to patients with rare diseases and their families must be based on research that prioritizes patient and caregiver input and provides an infrastructure for development and testing so that invested resources lead to tangible benefit. There are major obstacles, however, to developing, evaluating, and disseminating supportive care interventions for people with rare diseases.

In scleroderma, a rare autoimmune disease, the Canadian Institutes for Health Research funded the *Scleroderma Patient-centered Intervention Network (SPIN)* to develop a model for overcoming barriers and developing and testing high-quality resources that help patients cope with their disease. By bringing together a collaborative network of people living with scleroderma, researchers, and health care providers from over 30 sites and 8 countries, SPIN collects important data on challenges faced by people with scleroderma and is developing a series of support tools. Currently, 4 eHealth support tools are being developed for testing and dissemination to people with scleroderma from around the globe. All of these tools, once tested, will be made accessible to patients free of charge through patient organizations. The same innovative model used by SPIN can be used to develop, test and disseminate tools aimed at navigating life with other rare diseases.



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