

Where we are and where we are Heading

Rabi Tawil, MD

4th Rochester FSHD Patient Day

April 26, 2014

MEDICINE *of* THE HIGHEST ORDER



Welcome

□ Purpose: To provide individuals with FSHD and their families with an update on the state of research in FSHD

□ Speakers:

- Silvere van der Maarel, Phd, Leiden University Medical Center
- Stephen Tapscott, MD, Phd, The Fred Hutchinson Cancer Research Institute, Seattle
- Katherine Mathews, MD, University of Iowa
- Jeffrey Statland, MD, University of Rochester (Kansas University)

Acknowledgements

- Patient & family member panel
- Organizing:
 - Colleen Donlin-Smith: helped put together the program
 - Karen Lee: everything else

Find Gene



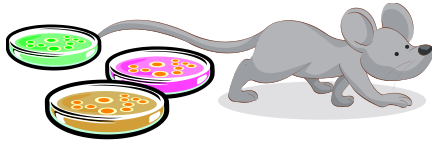
Find out what it Does



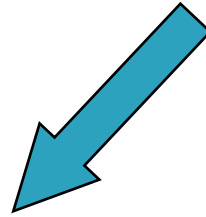
Drug Development



Screen Drugs

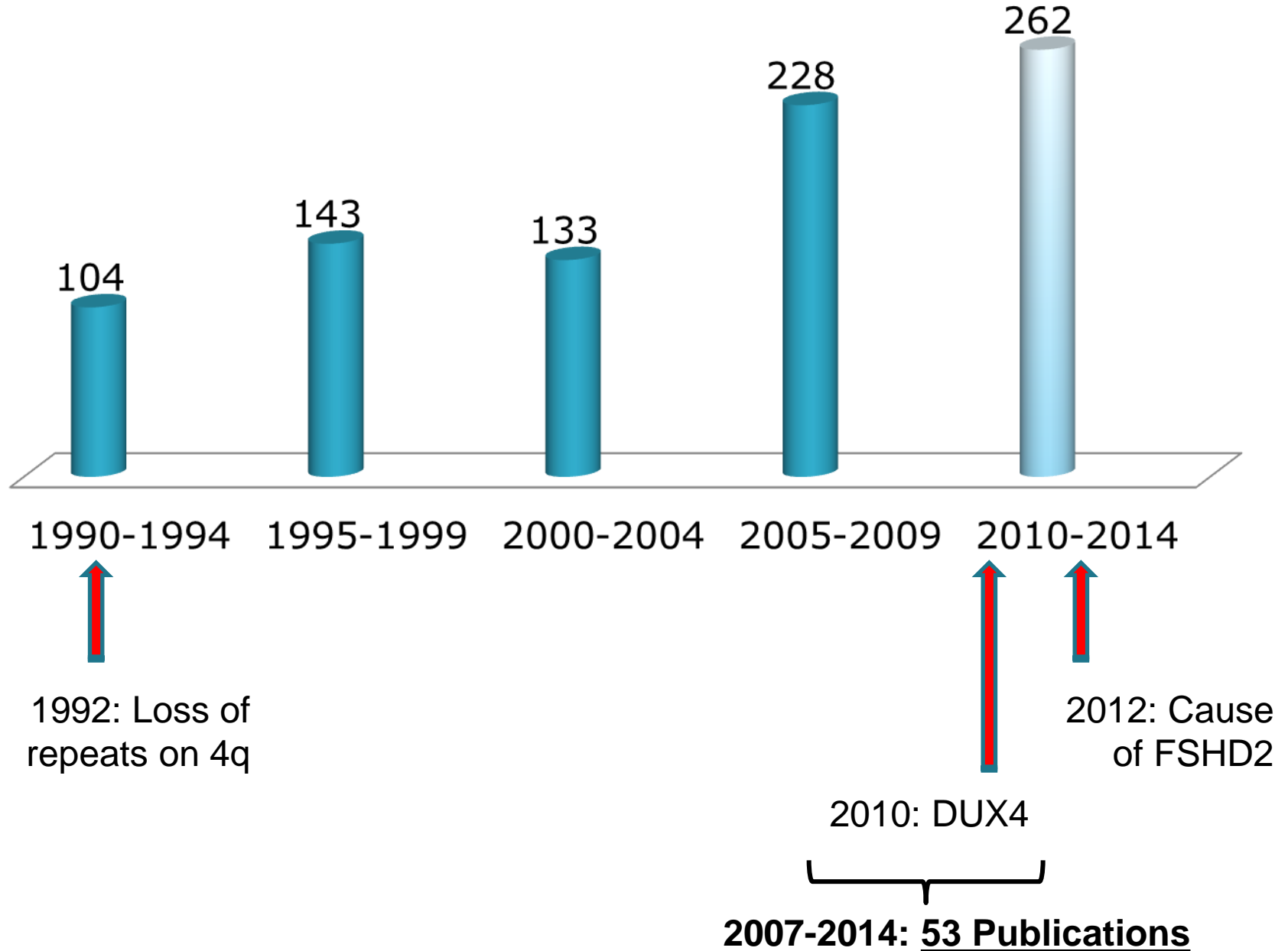


Trial Preparedness



**HUMAN
CLINICAL
TRIALS**

Number of FSHD Publications



Thank You for Your Support

- The advances made in the last five years could not have been made without the support of the community of individuals with FSHD and their families.
- Every sample of blood or tissue you give, every strange test we put you through and every endless questionnaire you endure serves a specific purpose

Modern Research is Teamwork!

friends
of FSH
research

• HUMERAL MUSCULAR •
FACIO-SCAPULO • DYSTROPHY •
fsh
• SOCIETY •



Prinses Beatri  Fonds
VOOR SPIERZIEKTEN

Geraldi Norton Foundation
& the Eklund Family

George & Jack Shaw
& the Shaw Family Foundation

Housekeeping

- ❑ Food and coffee will be moved to Classroom 502 next door
- ❑ Group photo at 12:50: you must sign consent form in your folder if you want to participate
- ❑ Parking: if you leave before 2pm you will need a parking validation
- ❑ Emergency exit: make a right on exiting classroom
- ❑ Bathroom: make a left on exiting classroom



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