

**RUDY**

**Uniting Patients and Researchers  
to Investigate Rare Diseases**

# Next steps

- Operationalize Rudy
  - Recruit
  - Assess
  - Bloods/ Urine/ Skin Biopsy/ Bone density
- Develop Rudy
  - Complete features development
- Secure medium term
  - Proposals – grant & industry

A conceptual image showing four hands of different skin tones (two darker, two lighter) arranged in a circle, holding a clear glass of water. The hands are positioned at the top, bottom, left, and right, with their fingers slightly curled around the glass. The water is clear and fills the glass. The background is plain white.

**Transparency  
in  
Partnership**

**Participant  
Driven  
Research**

**Transform  
Clinical  
Care**



# Bone Research Society ANNUAL MEETING 2014

25-26 June 2014, Sheffield, UK

ABSTRACT DEADLINE: 14 February 2014

*Approved for CPD by the  
Royal College of Physicians*

## Rare Bone Disease Workshop

*Organised by the Bone Research Society*

*In association with:*

*Arthritis Research UK Rare Bone Disease Topic Specific Group  
(Metabolic Bone Disease Clinical Studies Group)*

*Findacure*

24<sup>th</sup> June 2014 19:15 – 22:15

Rutland Hotel, Sheffield

 **Arthritis**  
Research UK

  
**BONE**  
RESEARCH SOCIETY

 findacure

**Eileen Shore** (Philadelphia, USA)/**Michael Whyte** (St Louis, USA): Why study rare bone diseases? + The USA perspective

**Kassim Javaid** (Oxford, UK): The NIHR rare disease musculoskeletal translational research collaboration

**Mike Briggs** (Newcastle-upon-Tyne, UK): 'ESDN', 'EuroGrow' & 'SYBIL' – 15+ years of EU network approaches for diagnosis and research of rare skeletal diseases

**Nick Bishop** (Sheffield, UK): Setting up an international consortium to facilitate research into paediatric bone diseases

**Lakshminarayan Ranganath** (Liverpool, UK): Progress in black bone disease, the National Alkaptonuria Centre and DevelopAKUre

**Nick Sireau** (Findacure): Building collaboration in rare disease research

**Gavin Clunie** (Cambridge, UK): Opportunities for optimising management of, and research in, rare bone diseases from UK NHS Specialised Services Commissioning

**Bone research society > satellite workshops >  
Tuesday 24<sup>th</sup> June 1915 onwards!**



# National Institute for Health Research

## Oxford

- Paul Wordsworth
- Raashid Luqmani
- Patricia Osborne



## Ann Underhill

- Oliver Gardener



- John Mills



VASCULITIS UK

1. Oxford	Wordsworth, Luqmani, Javaid, Wilkinson, Shine, Thakker, Mirzazadeh
2. Barts	Jawad
3. Birmingham	Gittoes, Shaw, Hogler
4. Bristol	Tobias, Burren, Clarke
5. Cambridge	Clunie, Poole, Shenker,
6. Cardiff	Stone
7. Edinburgh	Ralston
8. Glasgow	Ahmed, Gallagher
9. GOS	Van'tHoff, Bockenbauer, Hall
10. Imperial	Williams
11. Liverpool	Hannan, Beresford
12. Manchester	Selby
13. Sheffield	Bishop, Offiah, Eastell, McClosky, Arundel, Balasubramanian
14. Southampton	Cooper
15. Stanmore/UCL	Keen
16. National Hospital	Lachmann, Murphy
17. Newcastle	Aspray



