

## **Introduction to Best Practice for Pectus - Agenda**

- 1. Sincere welcome
- 2. Why we are here to publish best guidelines, to set standards for care and practice, to change policy in England. Looking to have patient support but aware of conflicts of interest and making sure they are 'protected' and not 'supported'.
- 3. What is SCTS and what is its role.
- 4. How SCTS have tried to influence NHS England and background to why / how NHS Eng have made the decision they have.
- 5. Update on urgent policy statement from NHSE for very severe cases.
- 6. Support of other organisations Royal College of Surgeons England, RCS Edinburgh, British Association of Orthopaedic Surgeons, British Association of Paediatric Surgeons, NHS Rare Diseases Advisory Group, Members of Parliament on behalf of their constituents.
- 7. Plans for February 2<sup>nd</sup> Venue, Timings, Programme
  - Patient / Parent involvement all welcome to attend (the RCS Library can hold 100)
  - If you have not yet registered, please register here
- 8. Potential for four talks from patients / parents:

## 12:55 - 13:15

- 2. Patient stories
- 2a Physiological Challenges
- 2b Psychological Challenges

## 13:50 - 14:10

- 5. Patent stories of going through surgery and if there were any benefits 5a Physiological benefit
- 5b Psychological benefit
- 9. Media involvement (Overseen by RCS England Communications / Press office, Nicola Kane) Potentially Sunday Times and BBC, Social Media.
- 10. Guidance for patients engaging with media
- 11. Potential for travel costs very limited conflicts of interest, charity, potential for limited 'zoned' support depending on distance
- 12. Any potential for patient / parent group to be set up / organised independent of SCTS? Long term aims to support patients and families with Pectus?