

Personal challenges

Dr Farrukh Shah

1. How long do you think you
will live?

2. Who old do you think
the oldest thalassaemia
major patient is?

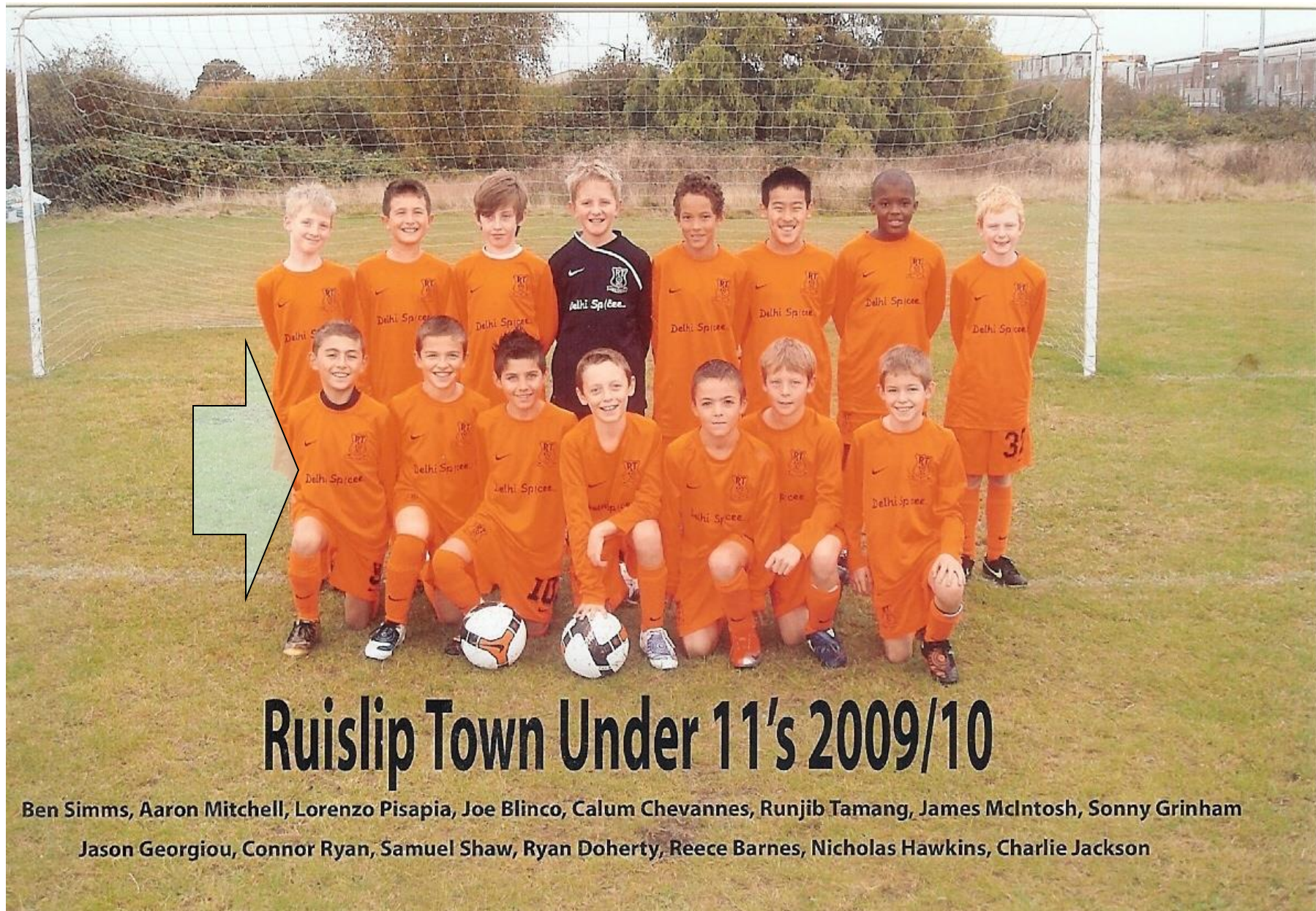
My child had thalassaemia

- Often met with shock and disbelief
- Stigma and shame
- How will I cope with my child?
- How long will my child live?
- Will my child suffer?
- How can I cure this?

Family settle into routine

- Must be handled with great care
- Child should be actively encouraged to participate on everything at school----no missing PE
- Responsible and encouraging attitude is very important in good outcomes
- Chelation to become a “normal part” of daily life
- Family education is critical from a young age





Ruislip Town Under 11's 2009/10

Ben Simms, Aaron Mitchell, Lorenzo Pisapia, Joe Blinco, Calum Chevannes, Runjib Tamang, James McIntosh, Sonny Grinham

Jason Georgiou, Connor Ryan, Samuel Shaw, Ryan Doherty, Reece Barnes, Nicholas Hawkins, Charlie Jackson

adolescence

- Real challenge!!!
- Rebellion----why me
- Testing of boundaries
- Childhood conditioning around treatment helps to limit this
- Talk to young adolescents in a language that they understand
- Expect them to self chelate by the age of 13-14
- Clinic and transfusion alone by 16/17

Whittington

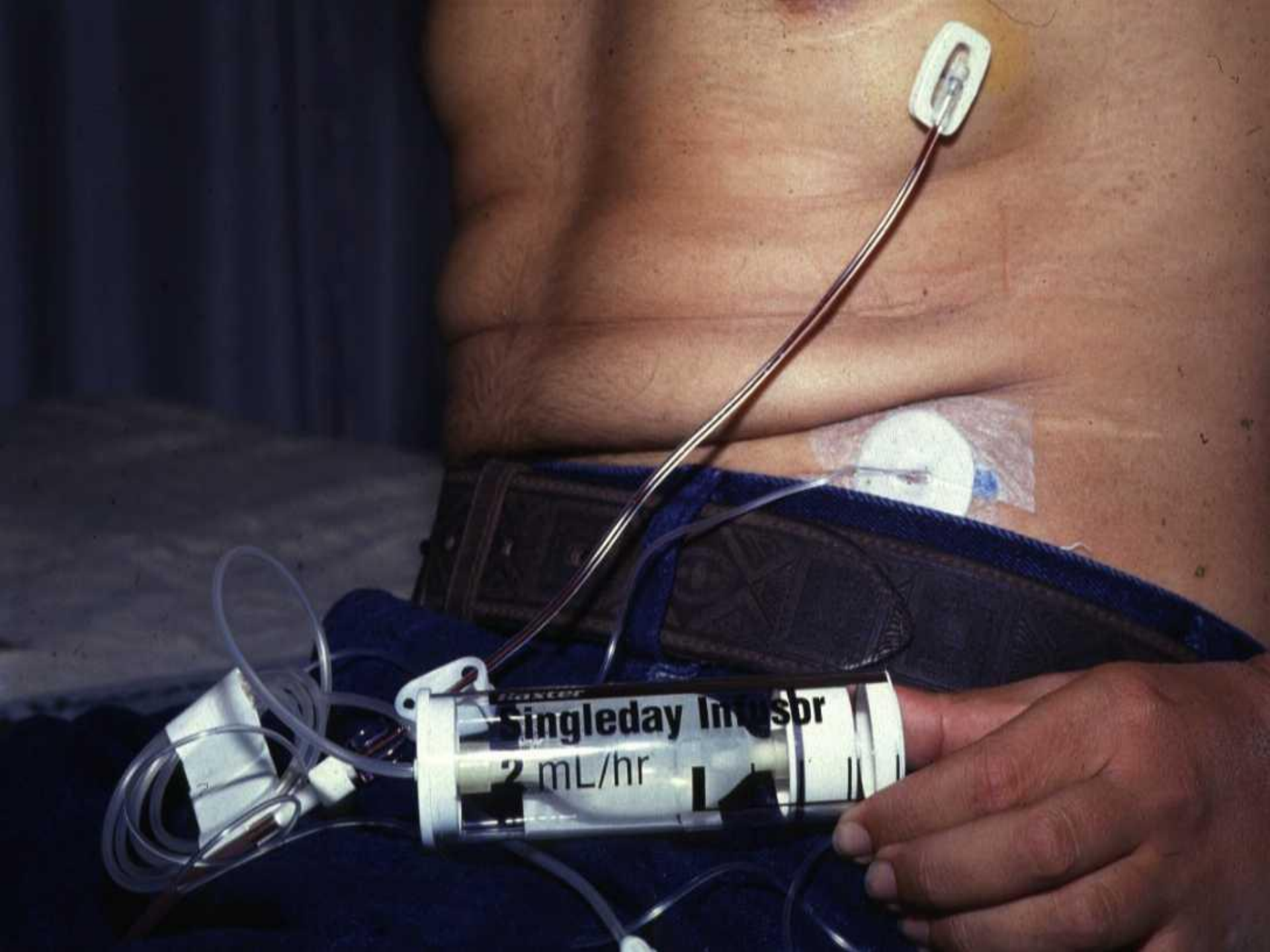
- Parental education starts before the first transfusion and continues through the first few years of life
- Children's education about their disorder starts from as soon as they start asking questions about it...play therapist, paediatric nurse specialist, genetic counsellors all involved.

University/leaving home

- Development of independence and confidence
- (if not self chelating without prompting they will stop treatment at this point!!)
- Strong links important to ensure young adults keep in touch about life issues
- Contraception/ understanding of genetics really important (transition work shops) in both intermedia and major patients

Work and careers

- Fully expect them to work full time
- WH: 4 doctors with TM, 1 judge, many lawyers, accountants, businessmen and women, work for tesco, asda, all sorts of roles
- Many patients are now parents
- Retirement??
- 4 in the next 5 years



Singleday Infusor
2 mL/hr

My love life

- Very difficult to introduce the health issues to partners/friends
- Encourage disclosure: easier with exjade and deferiprone , harder with desferal
- Stigma in many communities, (Greek, Turkish, Indian, Pakistani, Arab)..punishment from God etc..
- Difficult to find marriage partners for health siblings who are carriers
- Traits may be considered as diseased too.....
- Many cross cultural marriages of TM patients



Can I have children?







The future is bright
your life can be anything you want
it to be

Before I retire thalassaemia
patients will be transfusion free

Thank you!