

# How did I get here?

My journey from vitiligo patient to Cochrane Lead Author

*Maxine Whitton MBE*

# The beginning

- Born in Jamaica
- First sign of vitiligo - small patches on my knees – not a problem
- In my teens spread to my face (eyes and lips) impact on self-confidence, relationships
- 1959 arrived in London to do 'A' Levels, Hons Degree in French. Lived with my father
- Graduated UCL in 1965 and got teaching qualification in 1966 – taught French

# Early adulthood

- GP prescribed cosmetic camouflage - effectively disguised vitiligo on face where most apparent
- Married in 1969 – two children -after 2<sup>nd</sup> child born vitiligo spread to elbows and wrists
- 1985 joined Vitiligo Group – now Vitiligo Society
- In mid – 40's rapid spread – c. 70% of body affected - led to anxiety and despair
- Enlightened GP arranged psychotherapy at home then I went for 9 months to local practitioner – CBT great help

# Literature searches

- Left teaching in 1988, became a qualified academic librarian, job-sharing first in the Psychology Dept, then in the Biosciences Dept at NELP (now UEL)
- Taught students how to search the literature for their projects
- Had opportunity to do regular searches for studies on vitiligo
- Awareness of lack of studies on vitiligo compared to other skin diseases

# Introduction to Cochrane

- Talk by Hywel to nurses about the Cochrane Collaboration at BAD meeting – inspiring
- Realised I could contribute to research as lay person
- Later went to a meeting organised by CSG in London for Skin Charities and became a CSG member - CCNet
- Hand searched journals – learnt to recognise and evaluate RCTs
- Peer reviewer for CSG (lupus reviews)

# Why lead author?

- Frustration and anger at lack of good studies for vitiligo, no licensed treatment, general trivialisation of it
- No-one with special interest in vitiligo in UK at the time
- Poor knowledge amongst GPs
- Perceived a need to raise awareness of this disease
- If I didn't do it, no one else would

# Cochrane Review Author

- Encouraged by Hywel and Sir Iain Chalmers
- Terrified!!!
- Protocol not too difficult and completed and published in about 9 months
- Lots of training at UK Cochrane Centre – stats difficult
- Horrified at the poor quality of the 19 studies in the first review (2006)

# Challenges of being a consumer lead author

- Not a clinician or scientist – only a strong desire to do it – not sure I could, but would give it a go
- Organising work (roadmap), awareness of co-authors' commitments, all had important jobs but volunteers in Cochrane
- Had to get to grips with modern technology
- Working to deadlines, getting consensus on difficult issues
- Correspondence with study authors – not always successful

# First update of the review 2010

- Twice as many RCTs found in period since original review (38) Total of 57 studies assessed
- Still poor quality studies and many new interventions, mainly combinations with some form of light
- Two major operations so took a long time
- I decided I would not lead another review
- REALLY??!!!!

# Second update in progress

- Explosion of information – new genetic findings , now an autoimmune disease – inflammatory phase (not always apparent) especially at early onset
- Increase in published RCTs – 39 new studies - total included in this update = 96. More than 40 ongoing registered trials
- New interventions, more combinations of interventions
- Due to be published early in 2014

# Acknowledgements

- Everyone at CSG has been supportive and helpful over many years – Hywel has been my mentor, offering encouragement and advice - an inspiration
- All the co-authors, most of whom have agreed to work with me a second time
- My long suffering husband and family
- Definitely will not lead another vitiligo review!!!