The Link Between Research and Medical Care

Global Down Syndrome Research and Medical Care Roundtable

July 12, 2018  /  Brian Chicoine, MD  Medical Director Adult Down Syndrome Center
Disclosures

• Author

  - Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges
    Dennis McGuire, PhD & Brian Chicoine, MD

  - The Guide to Good Health for Teens & Adults with Down Syndrome
    Brian Chicoine, MD & Dennis McGuire, PhD
Adult Down Syndrome Center
Leo Foley
1907-1947
Life Expectancy

- Life expectancy:
  - 1907: 9 years
  - 1984: 28 years
  - Today: 60 years

- One of the oldest well-documented individuals with Down syndrome, 83 years old at death
Three (but not only three) Issues Linking Research and Patient Care

• Do no harm and safety
• Optimal ways to promote health and treat health problems
• Health care WITH people with Down syndrome
Do No Harm and Safety

• Health care guidelines project
  – What screening tests should be included?
  – What screening tests should NOT be included?
    • E.g. mammograms and colonoscopies

• Gaps in knowledge
Optimal ways to promote health and treat health conditions

• Many health issues to consider
• Life expectancy
  – Plateau
  – Age 50-62
  – Why?
• The next big research and patient care hurdle
• Alzheimer’s disease
• But all is not Alzheimer’s
Health Care WITH People with Down syndrome

• How do we include individuals with Down syndrome in their own health promotion?
• The balance between promoting independence and promoting health
• EDUCATION!!!!!
Health Information Retention

• How much do we retain?
• Why don’t we remember?
• What about people with an intellectual disability?
People with Down syndrome as teachers and peer supporters

- Peer support
- Conference
- Visuals:
  - Pictures, videos
  - Video modeling
  - Research
Resources

Web site – https://www.advocatehealth.com/health-services/adult-down-syndrome-center/ (or search for “Adult Down Syndrome Center)

Facebook – https://www.facebook.com/adultdownsyndromecenter

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Questions?
Discussion