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# **TRIS - Tracking Rare Incidence Syndromes: Developmental Matrix results**

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# Mission of the **TRIS** project

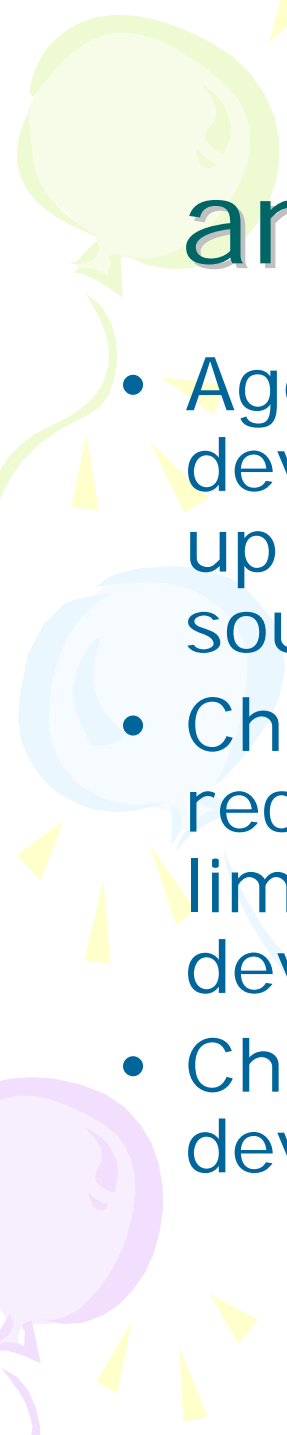
The Tracking Rare Incidence Syndromes (**TRIS**) project seeks to increase awareness and knowledge for families and professionals touched by rare trisomy conditions and aims to facilitate improved decision making for optimal services and supports for affected children and their families.

<http://web.coehs.siu.edu/Grants/TRIS/>



# The **TRIS** project seeks to increase knowledge...

- Baty, Jorde, Blackburn and Carey (1994) provide an overview of the developmental skills of children with trisomy 18 and trisomy 13.
  - SOFT families: 98 full t18; 32 full t13 children; 42% of children with t18 (N=41) and 38% with t13 (N=12) reached their first birthday
  - Examined seven skill areas: Cognitive, Communication, Receptive language, Expressive language, Social, Motor and daily living for 50 full t18 and 12 full t13; N=29 and 13, respectively, were survivors



# Baty, Jorde, Blackburn and Carey (1994) findings

- Age of achievement for a variety of developmental skills including held head up, laughed out loud, said consonant sounds, rolled over and cruised furniture
- Children's greatest achievement in receptive language and daily living skills; limited motor and communication development
- Children with full t13 had better developmental outcomes than t18



# TRIS Survey

- Development of **TRIS** Survey:
  - Content of Full (over two month survivors) and MODIFIED versions based on available literature and **TRIS** pilot data
  - Online survey methodology (see Hewson, Yule, Laurent & Vogel 2003; Witmer, Colman & Katzman, 1999)
- Over 230 in **TRIS** Participant database; received 91 completed surveys as of June 1, 2007 include 39 Full, 52 MODIFIED
- Developmental matrix only included in Full **TRIS** Survey; data available for 38/39 (97%)



# Developmental Matrix items

- Full **TRIS** Survey includes Developmental Matrix with 9 – 10 skills each from 1 to 60 months (N = 10; 1, 3, 7, 9, 12, 18, 24, 36, 48 and 60 months)
- How many children demonstrated sample skills in each interval
- Age range and trisomy sub/types



# Parent information: N = 39

- **Mother's age at conception**  
18 to 42 years;  $M = 31.6$  and  $SD = 6.40$
- **Present country of residence**
  - USA = 33 (85%)
  - Canada = 1
  - England = 2; Scotland = 1
  - Australia = 1; New Zealand = 1
- **Marital status** = 34/39 (87%) married
- **Education level**
  - 9 (23%) less than high school
  - 16 (41%) some or completed bachelor's degree
  - 10 (26%) some or completed master's degree
  - 4 (10%) more than master's
- **Income level** = 23 (59%) identified as middle income; 8 (21%) identified as low and high, respectively



# Child information for Full **TRIS** Survey participants: N = 39

- **Children with trisomy 18** = 10 (26% total sample)
  - Full = 6 (60%, 15% total)
  - Mosaic = 2 (20%, 5% total)
  - Partial = 2 (20%, 5% total)
- **Children with trisomy 13** = 18 (46% total sample)
  - Full = 13 (72%, 33% total)
  - Mosaic = 1 (6%, 3% total)
  - Partial = 4 (22%, 10% total)
- **Other rare incidence syndromes** = 11 including pt4p (N = 2), pt5q mosaic (N = 1), pt6p (N = 1), pt7q (N = 2), pt9p (N = 2), t15 mosaic (N = 1) and pt16 (N = 2)
- At time of survey completion (February – May 2007), **survival age** ranged from 3 to 326 months with 87% living (N = 34, *M* = 89 months; median (or midpoint) of distribution = 58 months) and 13% angels (N = 5; 3 – 290 months)



# Developmental Matrix: 1 month



- **Moves head when lying on stomach**
  - Demonstrates skill: 38 “Yes”
  - Age (N=26): Birth (N = 2; t13, t18 mosaic) to 8 months (pt9q)
  - “Dislikes being on tummy” (6 months, t13, 2006)
- **Coordinates sucking, breathing and swallowing**
  - Demonstrates skill: 32 “Yes”
  - Age (N=23): Birth (N = 9; 3 t13; 2 t18; 1 pt13; 1 t18 mosaic; 1 pt4p; 1 pt5q mosaic) to 12 months (pt9q)
  - “He was coordinated but it took him 45 minutes to finish an ounce” (birth, pt4p, 2004)

# Developmental Matrix: 3 months

- **Produces open vowel sounds**
  - Demonstrates skill: 28 “Yes”, 2 missing
  - Age (N=19): 2 months (pt4p) to 48 months (pt6p)
  - “Her crying is very special...” (6 months, t18, 2006)
- **Swipes at, grasps or shakes small toy**
  - Demonstrates skill: 34 “Yes”
  - Age (N=25): 1 month (t13) to 36 months (t18)
  - “More proficient when laying on back” (4 months, t18 mosaic, 2006)



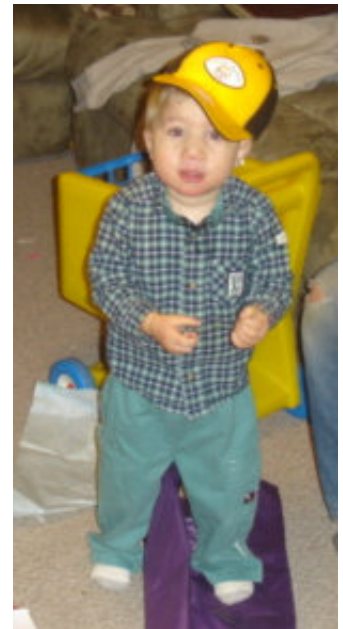
# Developmental Matrix: 7 months

- **Sits without support**
  - Demonstrates skill: 25 “Yes”, 1 missing
  - Age (N=21): 12 months (N = 2; t18, pt7) to 72 months (t18)
  - “Can only do this for few minutes only” (9 months, t13, 2003)
- **Indicates needs by crying or vocalizing**
  - Demonstrates skill: 36 “Yes”
  - Age (N=25): Birth (N = 9; 4 t13; 2 t18; 2 t18 mosaic; 1 pt4p) to 36 months (t18)
  - “Because of trach” (25 months, t13 mosaic, 2004)



# Developmental Matrix: 9 months

- **Crawls on stomach or crawls using hands and knees**
  - Demonstrates skill: 22 “Yes”
  - Age (N=18): 6 months (pt16) to 48 months (N = 2; 1 t13, 1 pt13)
  - “Rolled and scooted around at about 8 months, actually crawled on hands and knees later” (30 months, t13, 1993)
- **Responds to social games such as peekaboo**
  - Demonstrates skill: 24 “Yes”, 2 missing
  - Age (N=16): 4 months (N = 2; t13) to 72 months (pt18q)
  - “Giggles with physical actions” (4 months, t13, 2005)



# Developmental Matrix: 12 months

- **Takes steps with assistance**
  - Demonstrates skill: 24 “Yes”
  - Age (N=20): 5 months (t13) to 54 months (t13)
  - “Walks about 10 yards while holding his hands and can walk 4-5 house lengths down the sidewalk outside in his gait trainer” (24 months, t13, 2003)
- **Attempts to imitate simple gestures, signs and/or words**
  - Demonstrates skill: 17 “Yes”, 1 missing
  - Age (N=13): 11 months (t13) to 60 months (pt18q)
  - “Does some sign language” (15 months, t13, 2006)





# Developmental Matrix: 18 months

- **Scribbles with pencil or crayon**

- Demonstrates skill: 17 "Yes"
- Age (N=13): 15 months (pt5 mosaic) to 60 months (pt18q)
- "Makes marks but drops utensil" (20 months, pt4p, 2004)

- **Climbs up or down stairs with or without assistance**

- Demonstrates skill: 16 "Yes", 1 missing
- Age (N=14): 15 months (t13) to 60 months (N = 2; t13)
- "Just started doing this well" (48 months, pt13, 2002)





# Developmental Matrix: 24 and 36 months

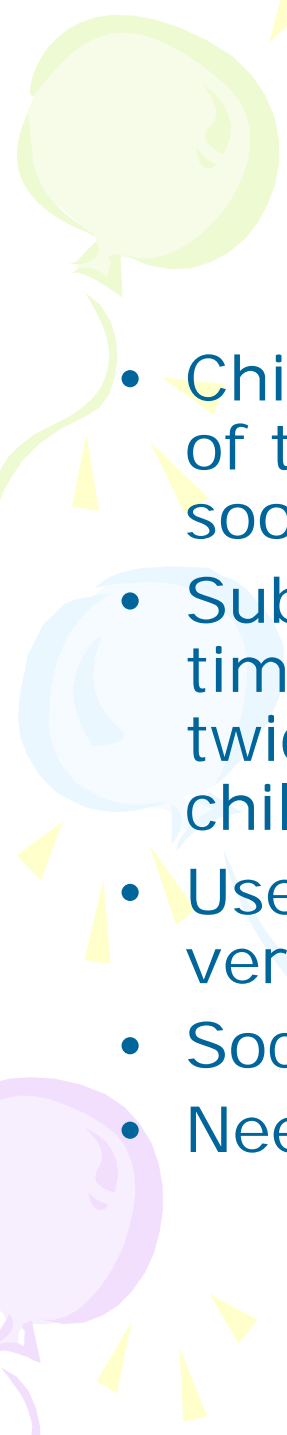
- **Attempts to throw or kick a ball (24 mos)**
  - Demonstrates skill: 18 "Yes", 1 missing
  - Age (N=14): 14 months (pt5q mosaic) to 120 months (t18)
  - "Loves to play ball, throwing, no kicking" (14 months, pt5q mosaic, 2005)
- **Asks / signs questions using "who", "what", "when" and "where"**
  - Demonstrates skills: 6 "Yes", 1 missing
  - Age (N=3): 25 months (pt7q) to 36 months (t13)
  - "Gestures and asks 'where is it?'" (25 months, pt7q, 2004)

# Developmental Matrix: 48 and 60 months

- **Shows basic understanding of time**
  - Demonstrates skill: 5 "Yes", 2 missing
  - Age (N=2): 55 months (t13) to 72 months (t13)
  - "Knows when it's morning, lunch and evening and relates what activities should happen at those times, will go to his bed when tired or at night, etc. " (72 months, t13, 1993)
- **Identifies primary colors, shapes, etc.**
  - Demonstrates skill: 9 "Yes", 3 missing
  - Age (N=5): 40 months (t18 mosaic) to 72 months (pt13q)
  - "Colours only at present" (40 months, t18 mosaic, 2003)







# Emerging data trends (N = 38)

- Children with t13 and/or partial or mosaic types of trisomies gain some developmental skills sooner than children with full t18
- Subset of early skills appear to emerge “on time”; while others emerge at approximately twice the number of months compared to children without a trisomy condition
- Use of gestures and/or signs for communication versus verbal communication
- Social skills appear to be a strength
- Need for additional data...



# Implications

- Importance of collecting developmental information on children with rare trisomy syndromes:
  - Update developmental milestones information (Baty et al., 1994)
  - Increase developmental expectations
  - Knowledge for basic daily care and medical needs



# Implications continued

- Importance of developmental information for professionals working with children with rare trisomies
  - Assessment including identification of strengths and emerging skills
  - Instructional planning and intervention targets
  - Monitoring developmental outcomes
  - Teaming (e.g., parent, physical therapist and SPED teacher)

# What's next for **TRIS**??

- Revision of **TRIS** Survey for Phase II data collection (begins February 1, 2008)
- Development of **TRIS** Follow-up Survey
- **TRIS** outreach efforts
  - Participant database
  - Contact professionals
- Continued **TRIS** Survey data entry, analysis and dissemination
- Continue to prepare **TRIS** conference proposals, manuscripts for publication, etc.



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