presents with age appropriate pre-verbal language skills and above average language comprehension and expression for her age.

AWESOMENESS REPORT

reports that she is really good at helping, noticing and cleaning up. Her smiles light up the room. A big huge grin - she radiates. You can't help but feel happy. She already has a sense of humour. She brings joy to the family every day.

and her family have been awesome to work with; committed and positive. It has been a pleasure being part of their team and I am very excited with the progress that has made.

RECOMMENDATIONS:

Treatment is complete therefore discharge from Speech language therapy.

If you have any questions regarding this report, please do not hesitate to make contact.

Best regards

Speech and Language Therapist
Tauranga Hospital, Bay of Plenty District Health Board

Conversation with mother of child who received this 'Awesomeness Report'. She really liked it.

1) As a descriptor of how child is not just what she can do.

2) Would be great for children who are really struggling

3) Keep to keep as a record of her child's learning & development journal.
SUPER POWER BABY PROJECT

Written and Photographed by Rachel Callander
“She changes people, their perspective on what is important, and brings out the best in them, inspiring them all in the process.”
Partial Trisomy 9q
due to Maternal 9/17 Translocation
Salma F. Atminos, MD, Joe J. Hsu, MD, Malcolm I. Pankey

A patient with partial trisomy 9q due to maternal 9/17 translocation was studied and compared with four previously reported cases. The clinical features allowed us to delineate a distinct clinical syndrome, which is characterized by psychomotor retardation, dolichocephaly, hooked nose, deep-set eyes, and long fingers and toes. There is an overlap among some of the features of this syndrome and those of trisomy 9.

T(9;17) for the distal part of the long arm of chromosome 9 (partial trisomy 9q) has been previously reported in four patients. We have studied a fifth patient with this disorder.

REPORT OF A CASE

The patient was born to a 35-year-old gravida II, para I, abortus I, mother at term. There were no antepartum problems, except for two episodes of urinary tract infection. Labor was induced because of decreasing levels of uterine cervix. Facial features were noted during labor, with episodes of tachycardia, bradycardia, and neonatal anemia of the arterial fluid.

The physical exam was 4 and 5 at 1 and 5 of the Arnold-Chiari classification. The birth weight was 1.39 kg, the birth length was 45 cm, and the head circumference was 32 cm. Examination demonstrated several dysmorphic features, which prompted a karyotype analysis. The baby fed poorly and failed to thrive. She was able to follow objects by 2 months of age, but at age 3 months she did not smile or babble. She was not able to lift her head or roll. Examination at 5 months of age (Fig. 1) through 3 revealed the following values: weight, 4.1 kg; length 60 cm; and head circumference, 42 cm. There was obvious dolichocephaly. The nose was long, big-eyed, and slightly hooked, with hypertelorism and hypotelorism. The ears were deep-set. The mouth was small, well-defined, and trident-shaped, and there was a narrow, high-arched palate. The skin was smooth and non-nodular. The hair was relatively fine and sparse, with abnormal folding of the fingers. The neck was short, with redundant loose skin folds posteriorly. The trunk was asymmetrical, the right side being more prominent, and the right eye was larger than the left.

There were bilateral renal adhesions, as well as double adhesions. The extremities were thin, and the fingers and toes were unusually long and thin. The fingers were held in flexion, and were clenched near the thumbs. There was an extra valve closure on both index fingers at the level of the middle phalanges. Dermatoglyphics were unremarkable. There was no acute clinical deformity of the feet. The wrists and heel pads were hypoplastic. There was severe limitation to hip abduction, and some limitation to knee extension. She had a weak, empty cry. The tone was poor. She had hypertonia in movements of the arms and legs in an asynergy manner.

A neonogram showed the long bones to be unusually long and slender. There were 11 pairs of ribs. The mental status was normal. There were scarring pericentral, malar, and minimal digits. The EEG and ECG were normal.

Fig. 1—Full view of patient with trisomy 9q, demonstrating facial, stenoglyph, strabismus, elongation of fingers and toes.

Partial Trisomy—Atminos et al

Chromosome preparations were made from lymphocyte cultures grown in the presence of 10 μg/ml of 3-bromodeoxyuridine and pulse with thymidine for the last six hours before harvesting. These were then stained with DNA-specific fluorescent dye (Hoechst), exposed to ultraviolet light, incubated in a solution of 0.3% sodium chloride and 0.03% tritium citrate at 60 °C and stained with Giemsa stain to produce DNA replication bands.

Analysis of such preparations from the patient demonstrated a 46,XX,17p+—karyotype (Fig. 2). The aterial chromosome 17 was inherited from her mother, who was found to carry a balanced translocation 9/17 (p22;p11) (Fig. 3). The patient is therefore trisomic for the region 9q32—qter.

COMMENT

Several cases of trisomy for the short arm of chromosome 9 (trisomy 9p) have been described and classified as a specific chromosomal syndrome. The main features of this syndrome include mental retardation, microcephaly, prominence forehead, hypertelorism, epicanthus, prominent nose, hypothalamic-pituitary and renal, mitral valve, absence of the C tria- dia, and micrognathia. A number of cases have been described of either complete trisomy 9 or trisomy 9 involving the short arm and a variable length of the proximal portion of the long arm. The clinical features included most of those of 9p trisomy, with additional features that were variable, depending on the length of

Fig. 3—Hand of patient with trisomy 9q, showing long fingers fixed and clubbed cover thumb.

partial, prominent forehead, hypertelorism, epicanthus, prominent nose, hypothalamic-pituitary, and renal, mitral valve, absence of the C triad, micrognathia. A number of cases have been described of either complete trisomy 9 or trisomy 9 involving the short arm and a variable length of the proximal portion of the long arm. The clinical features included most of those of 9p trisomy, with additional features that were variable, depending on the length of...
“GOD ONLY GIVES SPECIAL KIDS TO SPECIAL PARENTS.”

Irrelevant phrases, like:

- “Stay strong.”
- “Focus on enjoying every day you have.”

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“GOD ONLY GIVES SPECIAL KIDS TO SPECIAL PARENTS”

- Fluffy: Irrelevant phrases, like: 
  - "Special kids are only given to special parents."
  - "Stay strong."
  - "Focus on enjoying every day you have."

- Jargon: The parent/patient's level of health literacy is not considered. Medical terminology is used without explanation.

- Confusing: 

- Positive

- Negative

- Informative
“GOD ONLY GIVES SPECIAL KIDS TO SPECIAL PARENTS”

CONFUSION
The parent/patient's level of health literacy is not considered. Medical terminology is used without explanation.

NEGATIVE

DESTRUCTIVE
Language that is no longer acceptable in a cultural or social context. Uses subtractive, deficit words such as, mental retardation, abnormal, incompatible with life, dysmorphic.

INFORMATIVE

POSITIVE

FLUFFY
Irrelevant phrases, like:
“Special kids are only given to special parents.”
“Stay strong.”
“Focus on enjoying every day you have.”

JARGON


**FLUFFY**
Irrelevant phrases, like:
"Special kids are only given to special parents."
"Stay strong."
"Focus on enjoying every day you have."

**EMPOWERING**
Open-hearted language:
Information is disclosed clearly.
Ensures a parent leaves the room understanding what has been said.
Values are discussed and acknowledged.
Health literacy levels are identified and become a measure of how to best communicate further.

**CONFUSING**
The parent/patient's level of health literacy is not considered.
Medical terminology is used without explanation.

**DESTRUCTIVE**
Language that is no longer acceptable in a cultural or social context.
Uses subtractive, deficit words such as, mental retardation, abnormal, incompatible with life, dysmorphic.

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The image contains a Health Language Matrix diagram with the following quadrants:

- **Positive**
  - Fluffy
    - Irrelevant phrases, like:
      - "Special kids are only given to special parents."
      - "Stay strong."
      - "Focus on enjoying every day you have."
  - Empowering
    - Open-hearted language:
      - Information is disclosed clearly.
      - Ensures a parent leaves the room understanding what has been said.
      - Values are discussed and acknowledged.
      - Health literacy levels are identified and become a measure of how to best communicate further.

- **Negative**
  - Confusing
    - The parent/patient's level of health literacy is not considered.
      - Medical terminology is used without explanation.
  - Destructive
    - Language that is no longer acceptable in a cultural or social context.
      - Uses subtractive, deficit words such as, mental retardation, abnormal, incompatible with life, dysmorphic.

- **Jargon**
  - Irrelevant phrases, like:
    - "Special kids are only given to special parents."
    - "Stay strong."
    - "Focus on enjoying every day you have."

- **Informative**
  - Open-hearted language:
    - Information is disclosed clearly.
    - Ensures a parent leaves the room understanding what has been said.
    - Values are discussed and acknowledged.
    - Health literacy levels are identified and become a measure of how to best communicate further.

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For more information, visit [www.rachelcallander.co](http://www.rachelcallander.co)
When a Patient/Parent is empowered, they spend less time in Hospital, they cost the system less, they look after themselves better, they are given skills to succeed.

When the Patient/Parent feels powerless, the results include feelings of insignificance, an unwillingness to work together, anger and frustration. Lawsuits come from this space.

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What are you proud of?
What do you hope for?
What are you afraid of?
Rachel Callander

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