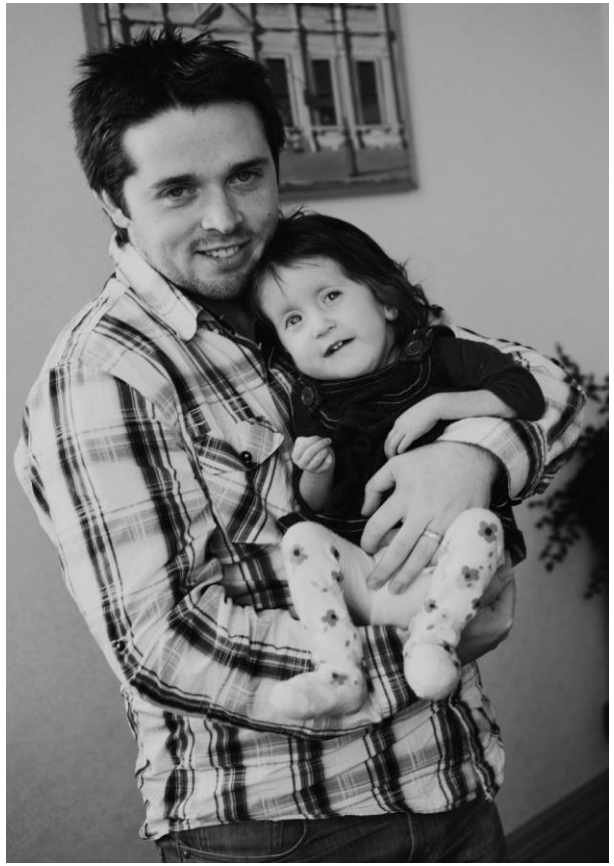
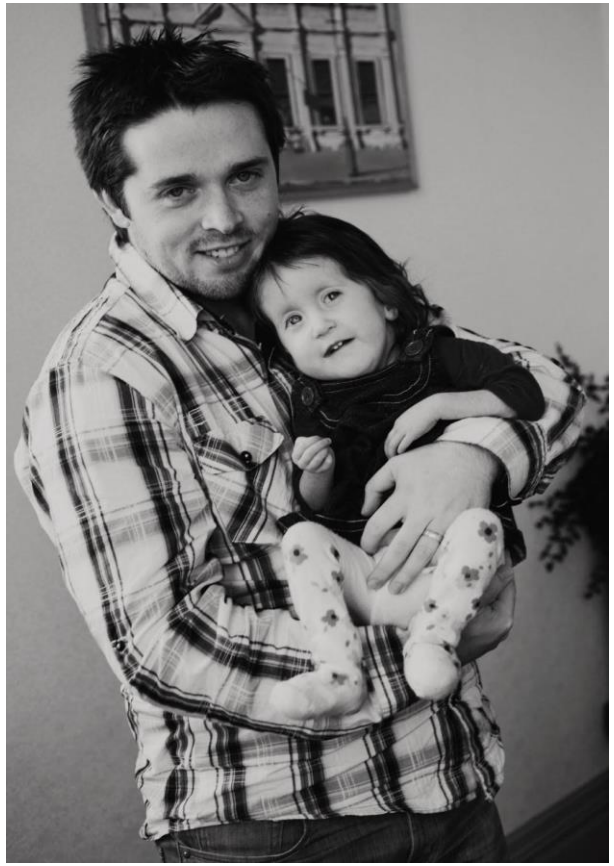

Rachel
Callander








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

AWESOMENESS REPORT

[redacted] reports that [redacted]s 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.

[redacted] 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 [redacted] 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

[redacted]

[redacted]

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

Conversation with Mother of child who received this 'Awesomeness report'. She really liked it

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

2) Would be great for children who are really struggling

3) Keen to keep as a record in her child's learning + development journal.

Written and Photographed by Rachel Callander













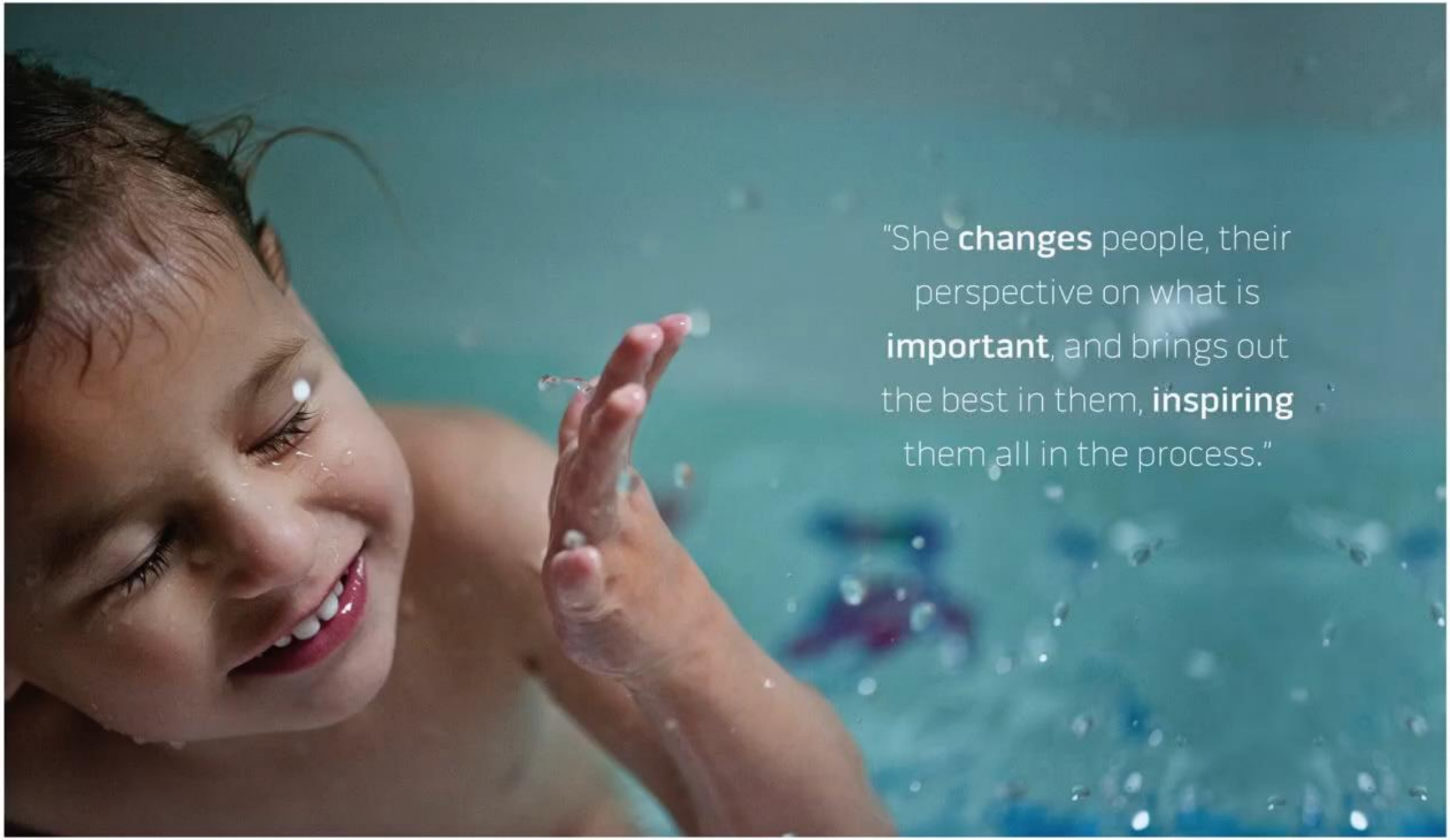











"She **changes** people, their perspective on what is **important**, and brings out the best in them, **inspiring** them all in the process."

Partial Trisomy 9q due to Maternal 9/17 Translocation

Salim F. Aftimos, MD; Joe J. Hoo, MD; Malcolm I. Parslow

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

(*Am J Dis Child* 134:848-850, 1980)

Trisomy for the distal part of the long arm of chromosome 9 (partial trisomy 9q) has been previously reported in four patients.[1-3] We have studied a fifth patient with this disorder.

REPORT OF A CASE

The patient was born to a 36-year-old gravida 5, para 3, abortus 1 mother at term. There were no antenatal problems, except for two episodes of urinary tract infections. Labor was induced because of decreasing levels of urinary estriols. Fetal distress was noted during labor, with episodes of tachycardia, bradycardia, and meconium staining of the amniotic fluid.

From the Departments of Paediatrics (Dr Aftimos) and Community Health (Mr Parslow), School of Medicine, University of Auckland, Private Bag, New Zealand, and the Institut für Humangenetik, University of Hamburg, Germany (Dr Hoo).

Reprints not available.

The Apgar scores were 4 and 7 at 1 and 5 minutes of life, respectively. The birth weight was 1,810 g, the birth length was 45.5 cm, and the head circumference was 33 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 5½ months she did not smile or vocalize. She was not able to lift her head or roll over. Examination at 5½ months of age (Fig 1 through 3) revealed the following values: weight, 4.2 kg; length 60 cm; and head circumference, 42.2 cm.

There was obvious dolichocephaly. The nose was long, fleshy, and slightly beaked, with hypoplastic alae nasae. The eyes were deep-seated. The mouth was small, well designed, and triangular, and there was a narrow, high-arched palate. The chin was small and receding. The ears were relatively large and square, with abnormal folding of the tragus. The neck was short, with redundant skin folds posteriorly. The trunk was asymmetric, the right side being more prominent, and the right nipple was larger than the left.

There were bilateral sacral dimples, as well as elbow dimples. The extremities were thin, and the fingers and toes were unusually long and thin. The fingers were held in flexion, and were clutched over the thumb. There was an extra volar crease on both index fingers at the level of the middle phalanx. Dermatoglyphics were unremarkable. There was nonpitting edema of the dorsum of the feet. The clitoris and labia minora were hypoplastic. There was severe limitation to hip abduction, and some limitation to knee extension.

She had a weak, hoarse cry. The tone was poor. She had stereotyped writhing movements of the arms and legs in an avoidance manner.

A roentgenogram showed the long bones to be unusually long and slender. There were 13 pairs of ribs. The cranial tables were thin, with discrete cortical margins and minimal diploë. The EEG and ECG were normal.

Fig 1.—Full view of patient with trisomy 9q, demonstrating facies, dolichocephaly, slender extremities, and long fingers and toes.

Fig 2.—Facies of patient with trisomy 9q. Note long fleshy nose, well-designed triangular mouth, and relatively large ears.

Fig 3.—Hand of patient with trisomy 9q, showing long fingers flexed and clutched over thumb.

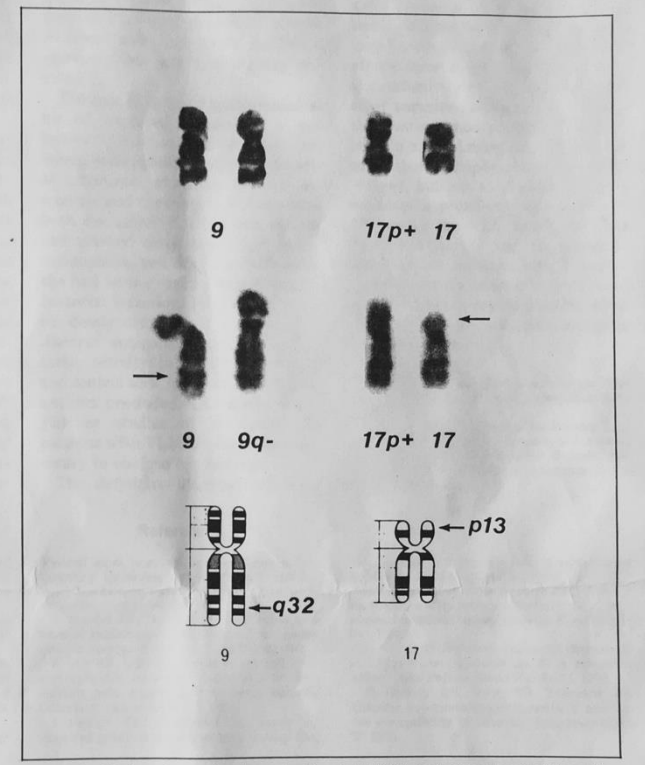


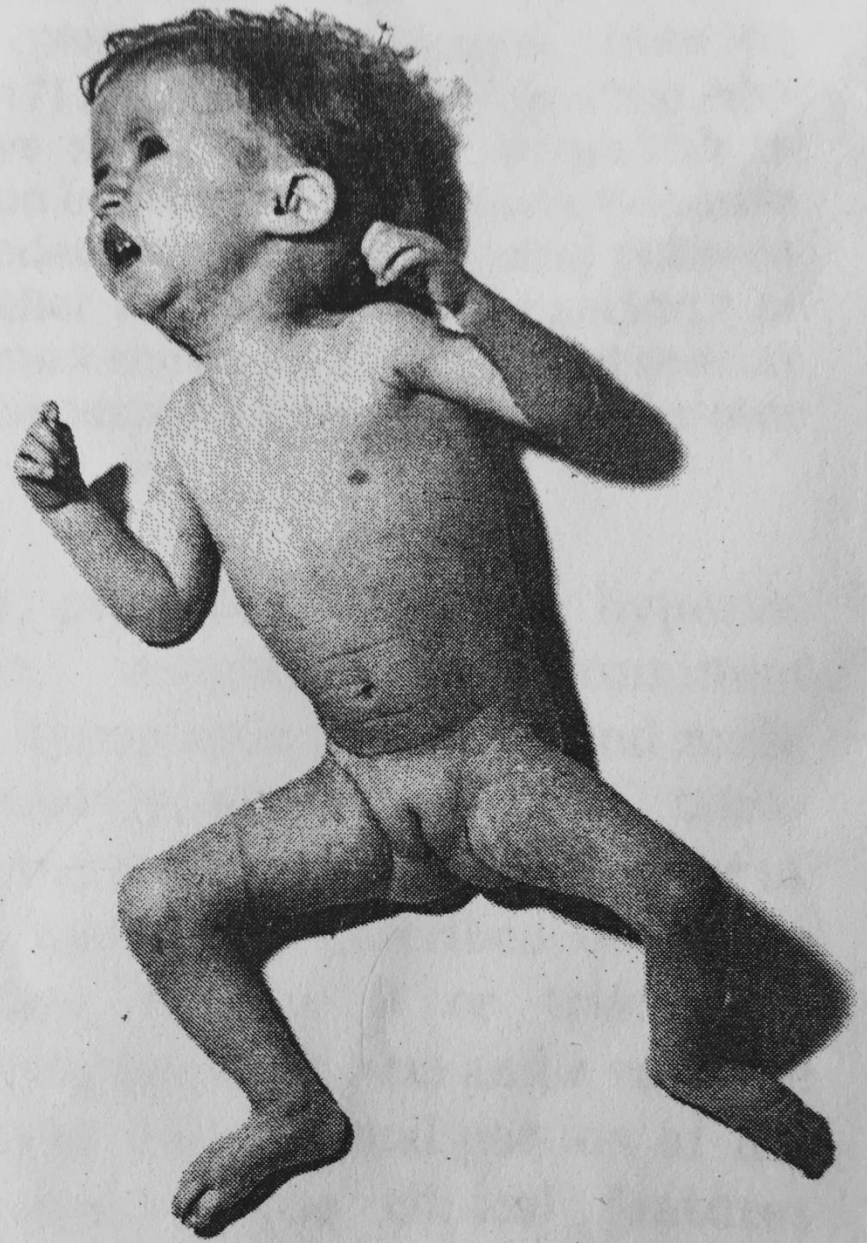
Fig 4.—Partial karyotypes showing pairs 9 and 17 (DNA replication banding) from the patient with trisomy 9q32→qter, 46,XX,der(17), t(9;17) (q32;p13)MAT (top), mother with balanced 9/17 translocation, 46,XX,t(9;17) (arrows show breakpoints in relation to normal chromosome of pair) (middle), and illustration of breakpoints (bottom). Because chromosome pictures are from DNA replication-banded preparations, banding patterns are similar, but not identical, to those obtained after standard Giemsa banding.[6] In particular, proximal region of long arm of chromosome 9 shows dark banding not seen in Giemsa-banded preparation. Pattern on rest of chromosome 9 long arm is same as that obtained after Giemsa banding.

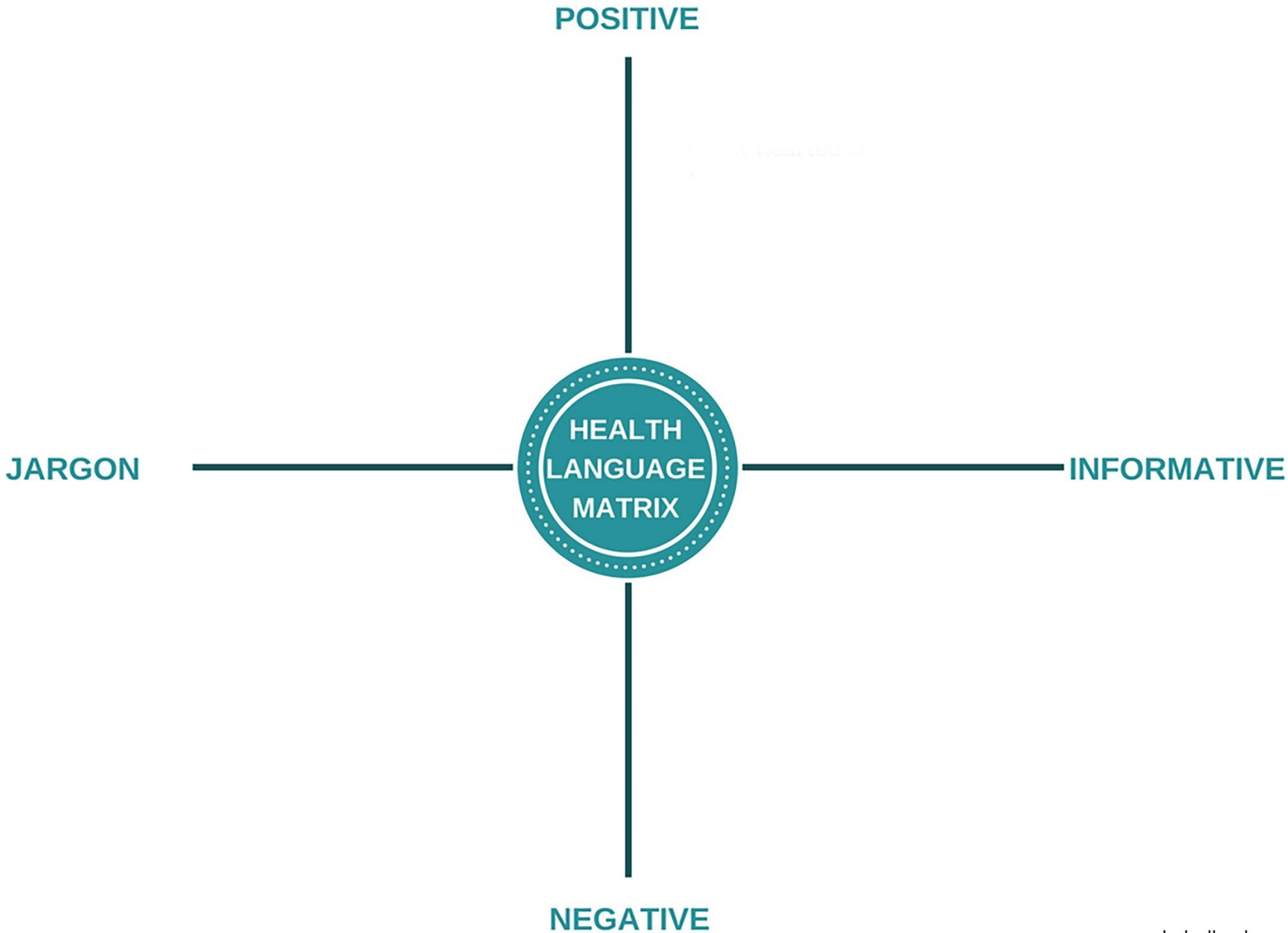
Chromosome preparations were made from lymphocyte cultures grown in the presence of 10 μg/mL of 5-bromodeoxyuridine and pulsed with thymidine for the last six hours before harvesting. These were then stained with DNA-specific fluorescent stain 33258 (Hoechst), exposed to sunlight, incubated in a solution of 0.3M sodium chloride and 0.03M trisodium citrate at 60 °C and stained with Giemsa stain to produce DNA-replication bands.[4,5]

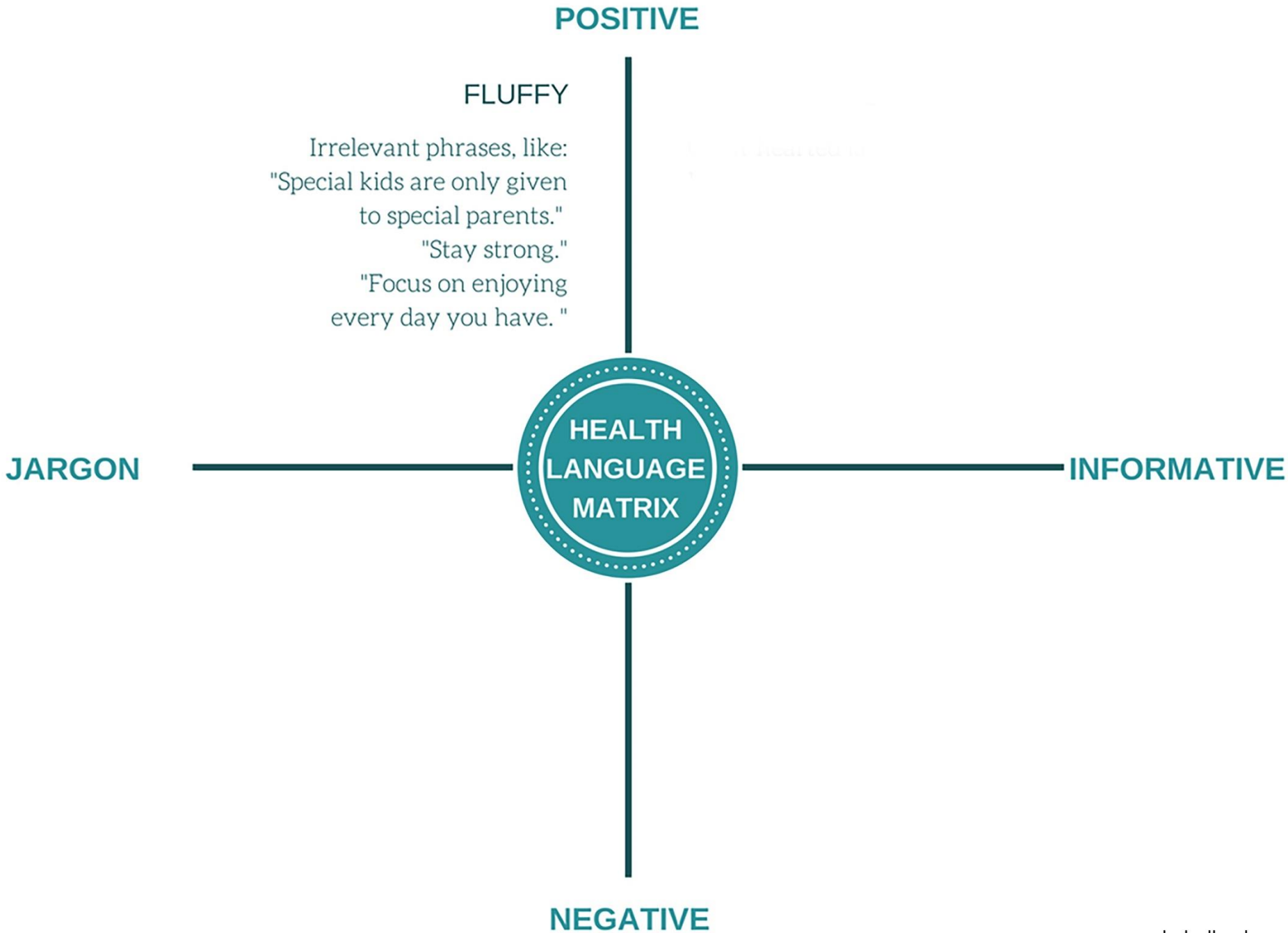
Analysis of such preparations from the patient demonstrated a 46,XX,17p+ karyotype (Fig 4). The abnormal chromosome 17 was inherited from her mother, who was found to carry a balanced translocation t(9;17) (q32;p13) (Fig 4). The patient is therefore trisomic for the region 9q32→9qter.

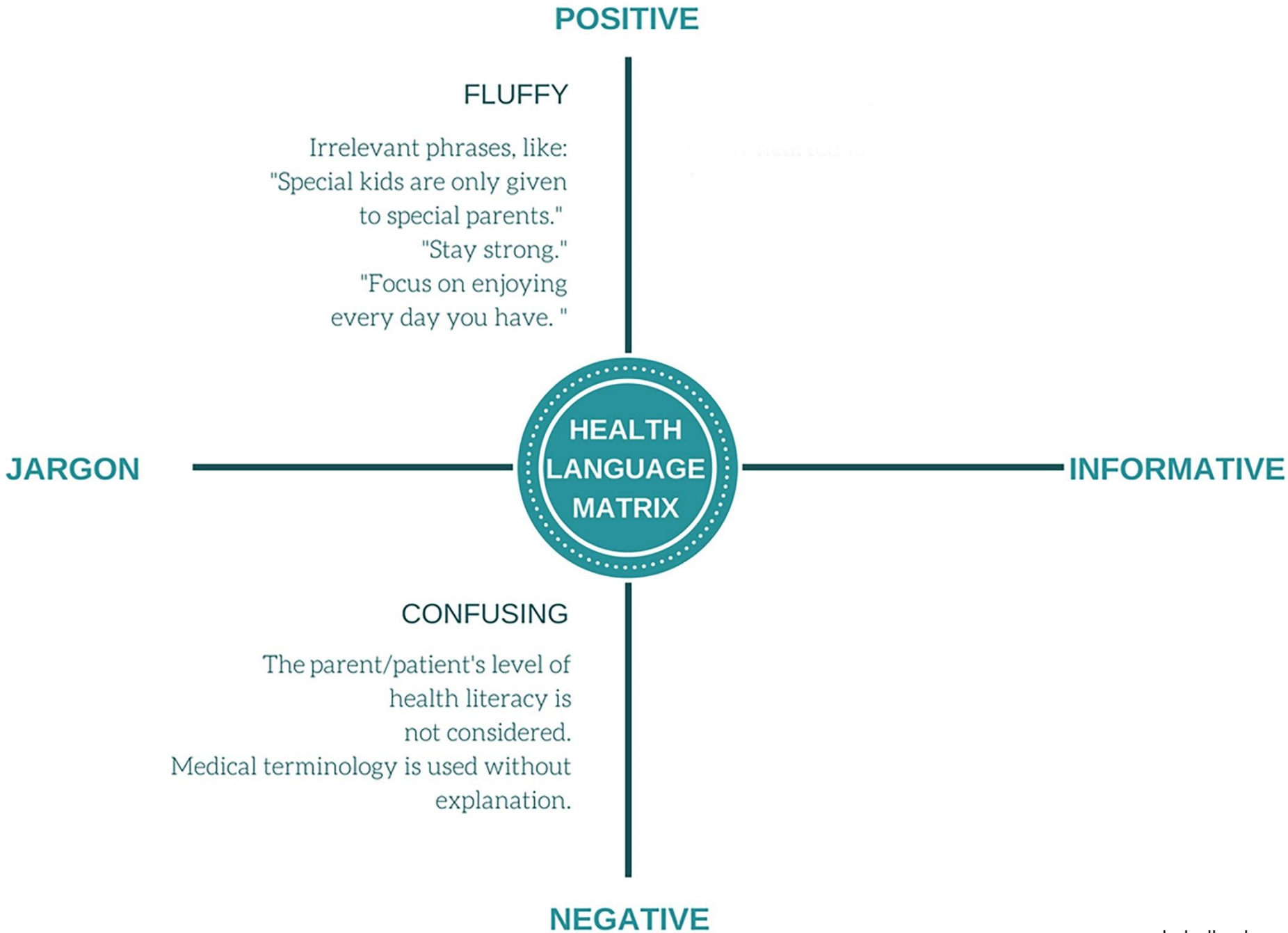
COMMENT

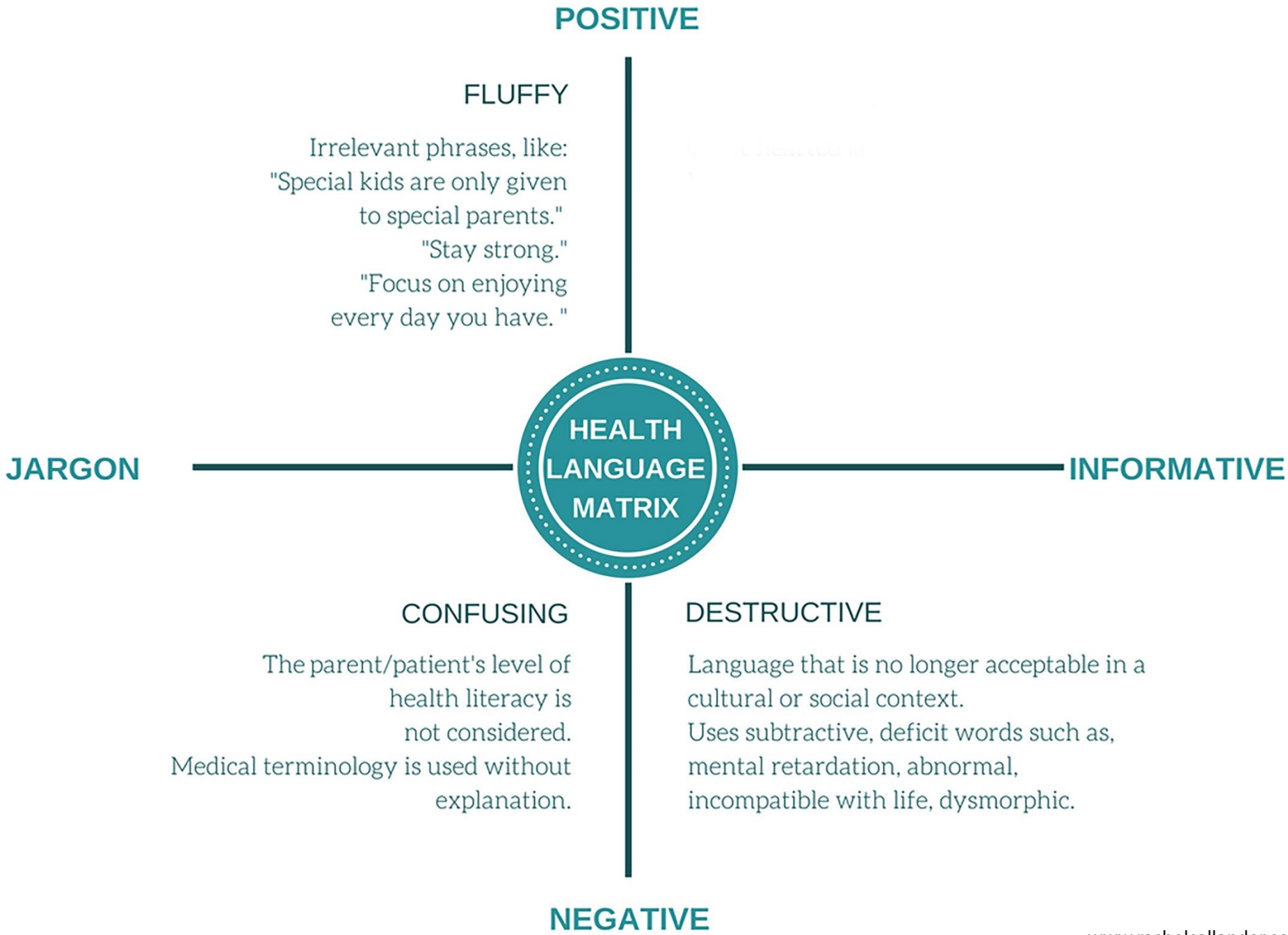
Several cases of trisomy for the short arm of chromosome 9 (trisomy 9p) have allowed the delineation of a specific chromosomal syndrome.[7,8] The main features of this syndrome include mental retardation, microcephaly, prominent forehead, hypertelorism, enophthalmus, prominent nose, hypoplastic phalanges and nails, clinodactyly, absence of the C triradius, and simian creases. 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.[9-13] The clinical features included most of those of 9p trisomy, with additional features that were variable, depending on the length of




POSITIVE
JARGON
HEALTH
LANGUAGE
MATRIX
INFORMATIVE
NEGATIVE


POSITIVE
FLUFFY
Irrelevant phrases, like:
"Special kids are only given
to special parents."
"Stay strong."
"Focus on enjoying
every day you have. "
JARGON
HEALTH
LANGUAGE
MATRIX
INFORMATIVE
NEGATIVE





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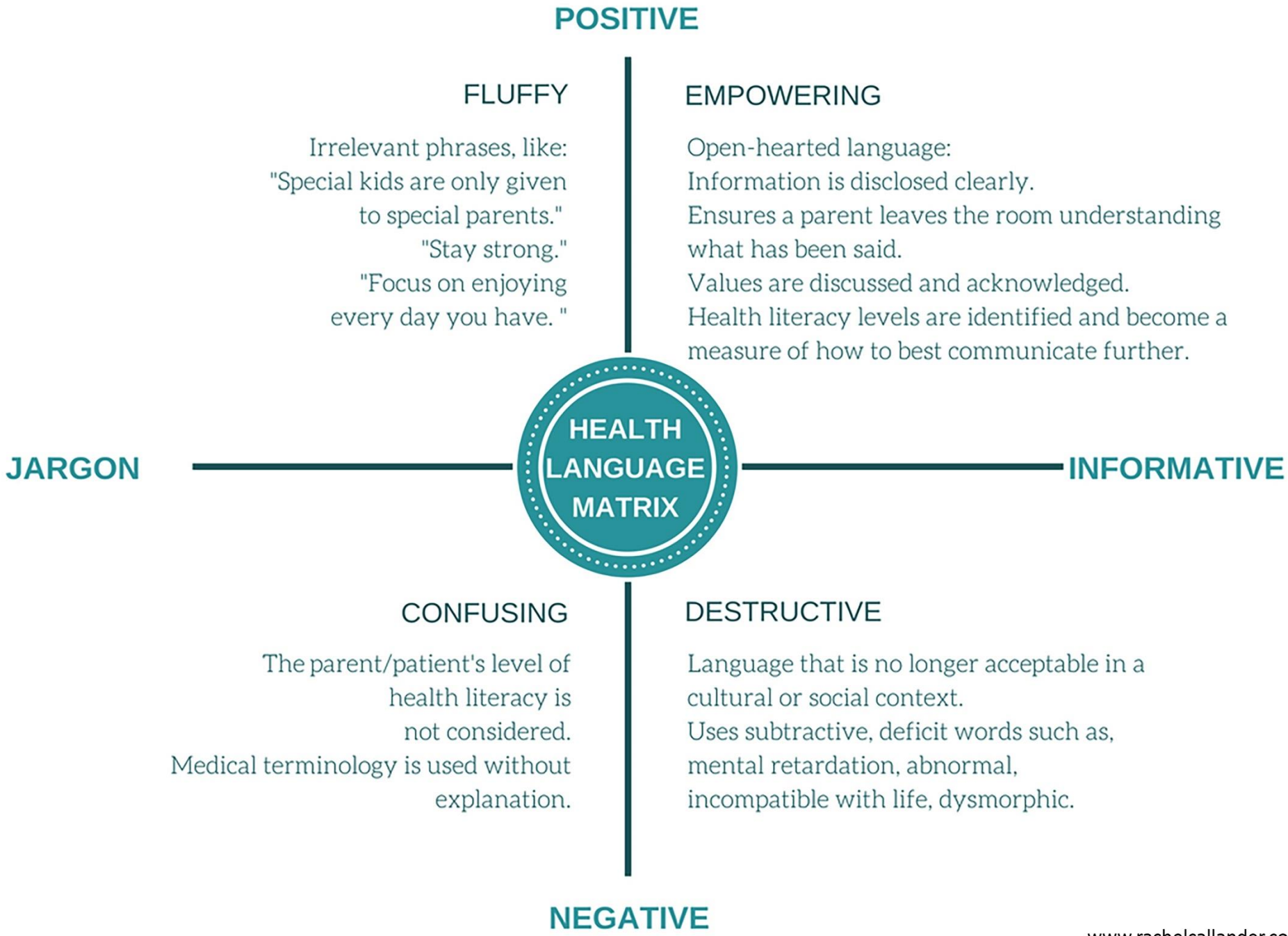

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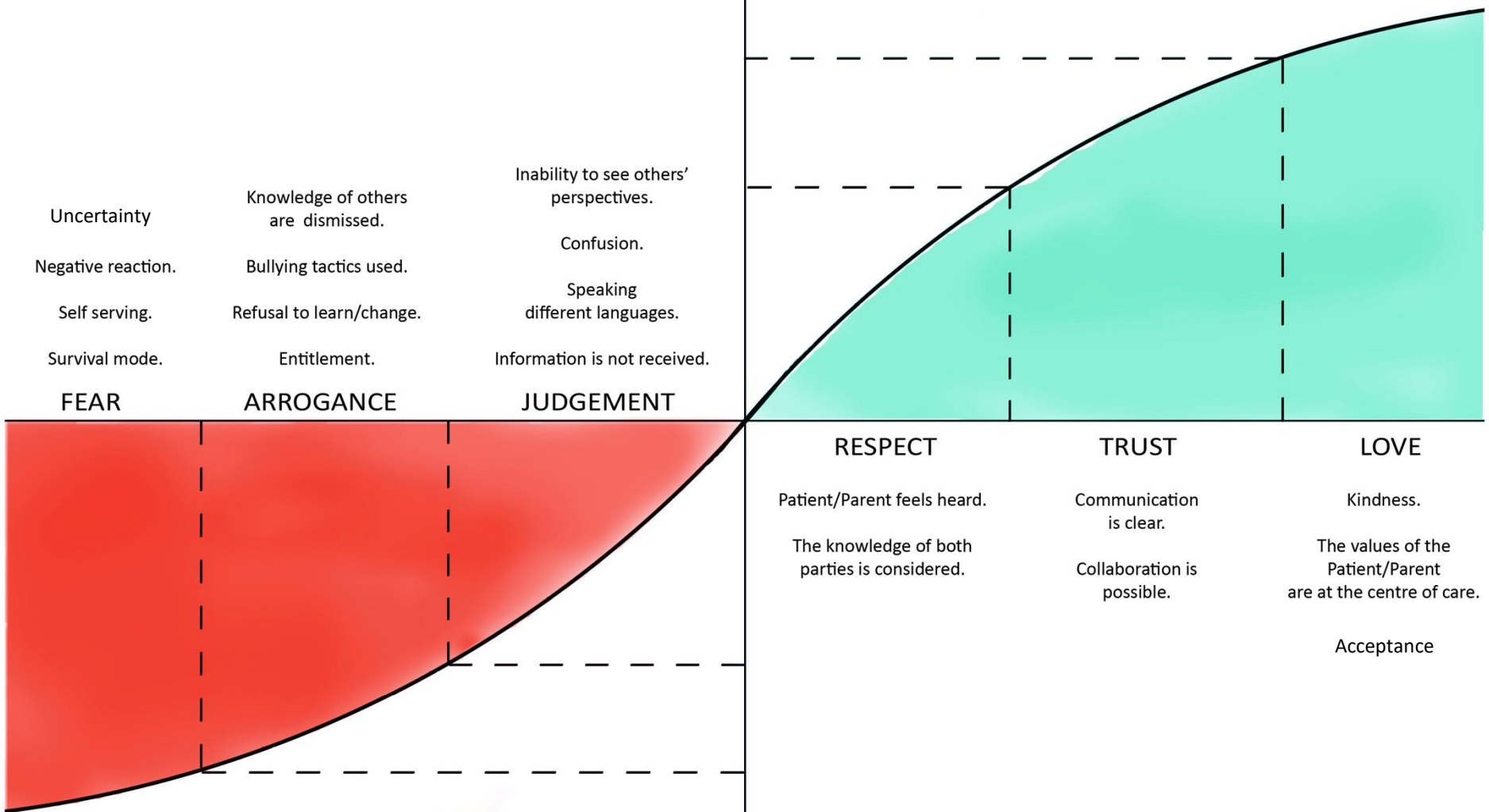
EMPOWERED

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.



Uncertainty

Negative reaction.

Self serving.

Survival mode.

FEAR

Knowledge of others are dismissed.

Bullying tactics used.

Refusal to learn/change.

Entitlement.

ARROGANCE

Inability to see others' perspectives.

Confusion.

Speaking different languages.

Information is not received.

JUDGEMENT

RESPECT

Patient/Parent feels heard.

The knowledge of both parties is considered.

TRUST

Communication is clear.

Collaboration is possible.

LOVE

Kindness.

The values of the Patient/Parent are at the centre of care.

Acceptance

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.

POWERLESS

What are you proud of?

What do you hope for?

What are you afraid of?

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