FACT SHEET ABOUT CORNELIA DE LANGE SYNDROME

Q. What is Cornelia de Lange Syndrome?
A. A disorder present at birth that results in severe physical and developmental disabilities.

Q. What causes Cornelia de Lange Syndrome?
A. It occurs as a result of a change in a gene in the developing embryo.

Q. What are some signs and symptoms?
A. There are many signs which can include:
   Medical/Physical Signs
   ~ Low birth weight
   ~ Slow growth
   ~ Small stature/Small head size
   ~ Thin eyebrows, long eyelashes
   ~ Short upturned nose
   ~ Thin down turned lips
   ~ Bowel abnormalities
   ~ Feeding difficulties
   ~ Excessive hairiness
   ~ Small hands and feet
   ~ Partial joining of the 2\textsuperscript{nd} and 3\textsuperscript{rd} toes
   ~ Incurved 5\textsuperscript{th} fingers
   ~ Gastrointestinal disturbances-GERD, constipation, diarrhea, poor appetite, vomiting, gaseous distention
   ~ Seizures
   ~ Heart defects
   ~ Cleft palate
   ~ Developmental delay
   ~ Hearing impaired
   ~ Visually impaired

Behavioral Signs
~ Hypersensitive to stimulus in the environment
~ Irregular patterns of eating, sleeping, and emotional responses
~ Self injurious behaviors (SIB) in response to pain or frustration
~ Lack of sensitivity to pain and/or a heightened sensitivity to touch
~ Short attention span, hyperactivity, and oppositional or repetitive behaviors
Q. What are some important tips for caring for someone with this syndrome?
A. These include:
~ Maintain adequate medical care by following physician’s orders for medications prescribed and notifying physician of any medical changes as medical conditions can increase behavioral signs such as SIB.
~ A well organize routine, with a predictable, calm environment.
~ Use communication tools to introduce changes-calendars, schedules, pictures.
~ Allow more time to process information and to complete activities.
~ Increase rest breaks can help to keep the individual stimulated to learn.
~ Teach with tangible, concrete objects.

Follow agency policy.

Source: APS HCQU PowerPoint Presentation – “Cornelia de Lange Syndrome”

For more information on this or any other physical or behavioral health topic, please call the APS HCQU office at 888-321-5861 or visit our website at www.hcqu.apshealthcare.com.

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