Kathryn W. Davis Global Community Scholarship
Community Service Project
Cornelia de Lange Syndrome Awareness

By Ingrid Barone and Siobhan Devaney
To provide awareness about a congenital syndrome called Cornelia de Lange Syndrome to future and practicing health care professionals at Westchester Community College. It is our hope that with this information they will someday make a difference with the identification of an individual or in the care of a patient with CdLS. We encourage them to carry this information into their professions and share it with fellow health care professionals.
Implementation

- Classroom presentations about CdLS to all current nursing students at WCC.
- General awareness to student and faculty body.
- Awareness to pediatric clinical Nurse Practitioners in the hospital setting.
What is CdLS?

- Congenital syndrome
- Caused by a genetic mutation
- Occurs in 1 in 10,000 live births
- Named after a Dutch pediatrician in 1933
Common Characteristics
Facial Features

- Long eyelashes
- Synophrys: eyebrows that meet in the middle.
- Short nose, broad or depressed nasal bridge
- Low set ears
Common Facial Features
Common Characteristics
Growth

- Small stature
Developmental

- Developmental delays
- Mental retardation
- Learning disabilities
Common Characteristics Behavior

- Obsessive compulsive characteristics
- Anxiety
- Self injurious behavior
- Aggression
- Autistic like features
Musculoskeletal

- Reduction defects with absent forearms
- Scoliosis
- Curved fifth finger
- Small hands and feet
Limb Anomalies
Most Common Challenges

- Developmental delays
- Heart defects
- Gastro-esophageal reflux disease
- Bowel abnormalities
- Feeding difficulty
- Hearing & speech problems
- Seizures
The Role of the Nurse

- Awareness of CdLS
- Assessment and plan of care
- Sensitivity and support towards family
The Family

- The grieving process
- Constant caretaking
- Many challenges
  - Financial
  - Marital
  - Social isolation
- Siblings
The CdLS Foundation

- Founded in 1981.
- Mission is to ensure early and accurate diagnosis.
- Reaching Out Newsletter
- Connect with other families.
- Promotes research.
- Info for professionals.
An estimated 20,000 individuals remain undiagnosed or without services in the USA.

Volunteers across the nation work to raise awareness in their community, among professionals and in the media.
CdLS **Awareness Presentations**

Powerpoint presentation to LPN and RN nursing students during classroom lecture time which focused on diagnosis, manifestations and nursing implications.
CdLS Awareness Presentations

- Students and faculty responded to presentation with interest and eagerness to learn more.
- Active discussion followed after each presentation.
Awareness to Educators

- Information to nurse educators.
- Incorporation of our CdLS powerpoint presentation into future RN lectures at WCC.
Awareness to Clinical Specialists

- Provide awareness to pediatric Nurse Practitioner at Westchester Medical Center.
April 2009: WCC Health Fair in the student resource center.

CdLS Awareness table with handouts, powerpoint display and CdLS foundation information.
WCC Health Fair

- Active dialogue and Q&A with students, faculty and campus employees.
For more information ...

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