Introduction: Overcoming Barriers to Successful Epilepsy Management

December 4, 2011

Joseph I. Sirven, MD
Professor and Chairman
Department of Neurology
Mayo Clinic in Arizona
How To Vote via Texting

1. Standard texting rates only (worst case US $0.20)
2. We have no access to your phone number
3. Capitalization doesn’t matter, but spaces and spelling do
Introduction: Overcoming Barriers to Successful Epilepsy Management

December 4, 2011

Joseph I. Sirven, MD
Professor and Chairman
Department of Neurology
Mayo Clinic in Arizona
Disclosure

• Research: UCB, Neuropace, National Institutes of Health
• Boards: Epilepsy Foundation, Doximity
• Time compensation: Epilepsy Therapy Project (editor: Epilepsy.com)
• Royalties: Up to Date
How Well Are We Doing?

- Time since last seizure
  - < 1 wk: 10
  - 1-3 wk: 10
  - 1-4 mo: 10
  - 4-12 mo: 16
  - 1-2 yr: 10
  - >2 yr: 20

57% < 1 year

% of patients

Fisher et al *Epilepsy Res* 2000
44.9% of patients with epilepsy report having had a seizure in the previous year – Of these 65.1% reported more than 1 seizure in the preceding 3 months

42.1% of patients with epilepsy report that their epilepsy limited their activity over the preceding year
Index Case: The Dixon-Salazar Story

• “My daughter Savannah was healthy and typically developing until age 2.
• Seizures began abruptly after being awakened to the sound of Savannah shaking and gagging.
• We didn't know she was seizing; we thought she was choking. Doctors called her seizures attacks and spells, but never seizures, and we were repeatedly assured she would "outgrow them".
• Savannah is now 15 and seizes daily.
• She is intellectually disabled from the seizures and will never be independent.”

Tracy Dixon-Salazar, PhD
IOM Public Testimony
The Dixon- Salazar Story: Index Case- Medical

• “15 years of epilepsy by the numbers
  – Seizures to date - 27,949
  – Years before diagnosis - 3
  – Neurologists we saw before diagnosis - 7
  – Epilepsy treatments tried to date - 26
  – Treatments that have stopped her seizures - 0
  – Cause of her epilepsy – unknown”

Tracy Dixon-Salazar, PhD
IOM Public Testimony
The Dixon- Salazar Story: Index Case- Financial

• “Monthly cost of Savannah's current 5-drug regimen - $1,640
• Times she needed emergency rectal medication to stop her seizures last month - 7
• Cost of one PR Med - $183 ($183 x 7 = $1,281)
• Epilepsy-related hospitalizations (including 3 surgeries) - 11
• Cost of Savannah's last hospital stay - $53,475”

Tracy Dixon-Salazar, PhD
IOM Public Testimony
The Dixon- Salazar Story: Index Case- Life Numbers

- “Days of school she's missed so far this year - 43 (out of 121 days)
- Years she's had an IEP - 12
- Years we've had to fiercely advocate for an appropriate education under that IEP – 15 years
- Time in a day that Savannah can be left unattended – 0”

Tracy Dixon-Salazar, PhD
IOM Public Testimony
The Dixon- Salazar Story: Index Case- Life Numbers

- “Times I was late to work last week because of seizures - 2
- Times my husband and I have been on the brink of divorce because of epilepsy - 3
- Times I've been clinically depressed since her diagnosis and needed treatment - 5
- Times we've had to cancel an outing because of seizures - ???
- Years Savannah will live before the seizures kill her - ???

Tracy Dixon-Salazar, PhD
IOM Public Testimony
The Dixon- Salazar Story: Index Case- Life Numbers

• “What do we need?
  – In the early years, we needed:
  – To be told she had epilepsy. Tiptoeing around the diagnosis robbed us of precious time.
  – We needed the facts…….”

Tracy Dixon-Salazar, PhD
IOM Public Testimony
The Index Case Shows

- Diagnostic and Physiological Barriers
  - Classification
  - Diagnosis
  - Physiology/Etiology
- Therapeutic Barriers
  - Antiepileptic drugs (AEDs)
  - Surgery
  - Comorbidities
The Index Case shows

- Public Health Barriers
  - Stigma
  - Access
  - Finances
  - Laws
From the Index Case to the AES Annual Course

- Course divided into 3 Major Groups of Barriers
  - Diagnostic/Physiological
  - Therapeutic
  - Public Health
- 5 Illustrative Cases
- Combination of Lectures/Panels/Debates
- Present Solutions as well as Outlining Barriers