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Treating kids with CFS
Pennsylvania doctors learn from noted clinicians

By Patti Schmidt

The CFIDS Chronicle July/August 1998

Lehigh Valley Hospital and the CFS Association of the Lehigh Valley sponsored a seminar May 20 called "Chronic Fatigue Syndrome in Children and Adolescents."

Herbert L. Hyman, MD, a gastroenterologist who treats many Allentown, Pa.-area CFS patients, John D. VanBrakle, MD, pediatrics department chairman, Lehigh Valley Hospital, and the hospital's Center for Educational Development and Support sponsored the series. Featured speakers were David S. Bell, MD, and Charles W. Lapp, MD, both well known for their experience with young people with CFS (referred to as chonic fatigue syndrome or CFS rather than CFIDS in medical research and, therefore, in this article).

The event consisted of an afternoon session for medical professionals and an evening session for patients, friends and family members.

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Diagnosing kids & adolescents

After a brief introduction, Dr. Bell, also well known for his research, talked about treating PWCs for more than a dozen years. In 1985, he identified an outbreak in his small community of Lyndonville, N.Y., as a distinct illness. His talk focused on diagnosing children and adolescents.

"It's been frustrating to those of us who study CFS that no one medical specialty has come forward to claim the illness. I feel it should be the general practitioner or pediatrician," he said.

Bell pointed out the controversy surrounding diagnosing children less than 10 with CFS and said most doctors won't feel comfortable doing so until a better definition is decided upon. With young children, he pointed out, it's often difficult to quantify their symptoms.

"Sometimes kids have no previous state of non-fatigue to compare their present fatigued state to," reminded Dr. Bell. After age 10, he said most kids find it easier to talk about their symptoms.

Gradual onset typical

Dr. Bell has found that although adults are more commonly hit with an acute onset, children more often become gradually ill with CFS, and while in adults CFS is diagnosed more often in females, in kids both genders get it equally.

Despite the controversy in diagnosing young children, Dr. Bell finds CFS tends to have a "very characteristic symptom pattern" in children.

"The child may look healthy, but you'll find that functionally, he's not," said Bell. His study found that children have rashes, abdominal pains and dizziness more often than adults.

Dr. Bell divided his CFS diagnostic presentation into four parts: fatigue, neurologic difficulties, pain and sensitivities.

Fatigue, he said, is an inaccurate term for what PWCs feel.

"Asthenia is a more accurate description," he said, "meaning loss or lack of bodily strength, weakness, debility. The fatigue occurs abruptly, is often mixed with orthostatic intolerance and is made worse by exertion."

Kids learn how to work around their activity limitations naturally, he noted. They'll be more active at a certain part of the day when their bodies allow them to be; they'll also tend to be more tired at certain parts of the day.

A slide with Karnofsky scores in hour-long periods showed the typical ups and downs of a PWCs daily fatigue fluctuations. He also showed a graph that plotted a PWCs energy levels over a month-long period. This kind of graphing would be helpful for PWCs of any age, because it shows individual fatigue patterns.

"You also might find neurologic problems in these kids," Dr. Bell told the medical professionals present. "Cognitive dysfunction, balance disorders, parasthenia and dizziness are common."

Pain can also be a part of CFS for many children, he said. In a recent study of pediatric PWCs, 70 percent of them had fibromyalgia. "I think it's the same illness," said Dr. Bell.

Sensitivities help in diagnosis

Sensitivities are also common in pediatric CFS, he noted. Many kids are sensitive to light, noise, odor, drugs, temperature changes and foods. This does not happen in hypochondriasis, he noted, and can be used to rule that out.

The biggest difficulty in pediatric CFS may be the emotional toll it takes, he said. "Children get confused when they're sick with an illness like CFS," said Dr. Bell. "They wonder, are they sick or is it an emotional issue?"

He spoke about kids having "health identity confusion," in which they mix up who they are with why they're sick. Appropriate counseling can help, but he said that nothing takes the place of caring, supportive parents and a family doctor who believes the child and takes his or her complaints seriously.

One of Dr. Bell's recent studies of 214 adults and 47 kids found CFS occurs in families more often than previously reported. During the evening session, Dr. Lapp reported that Dr. Walter Gunn, formerly of the Centers for Disease Control (CDC), had told him privately that they'd found a 10%-15% occurrence in families.

About 80 percent improve

Bell has continued to follow his outbreak patients, and has found that 37% of the CFS cases resolved completely; 42% are well, but are not completely resolved; 11% remain quite ill; and 8% are very ill.

"So after 15 years," he said, "80% have a satisfactory outcome, and 20% an unsatisfactory outcome."

Of those in his study, no one recovered within 12 months of onset. Twenty-two percent recovered within 12-23 months of onset; 11% recovered within 24-35 months of onset; 33% recovered within 36-48 months of onset; and 33% recovered after four years or more.

"I haven't found that CFS is short-lived in my pediatric patients," said Dr. Bell. Previously, the NIH has said that CFS in kids usually resolves itself within two years.

His study also found that CFS has a profound impact on education for young PWCs. Forty percent missed little or no school; almost 23% missed up to six months; almost 9% missed between six and 12 months; almost 6% missed between 12-24 months; and almost 23% missed more than two years of school.

"The amount of school missed is an important indicator of outcome," he noted. In other words, the more school a child misses, the more likely it is that he' ll be sick longer.

Seeing kids' points of view

Dr. Lapp, director of the Hunter-Hopkins Center in Charlotte, N.C., and associate clinical professor at Duke University Medical Center, talked about CFS management from the viewpoint of a practicing clinician.

"Kids with CFS are frustrated and angry at their doctors," said Dr. Lapp. "But once diagnosed, they feel relief and closure. I tell my patients that most people get better over time. It might be years until they feel better, so I tell them they must develop coping strategies."

Lapp's initial suggestions: avoid strict bedrest and balance light activity with frequent rest. Stretching is important, he said, so yoga and tai chi are great.

"I teach all my patients to deep-breathe and to watch their posture," he said. "Interval exercise has been found to be helpful in Ben Natelson's clinic, so I recommend interval exercise for many of my CFS patients," he said. "Find something you like to do, do it for five minutes, rest, do it again for five minutes, then rest again."

Lapp believes hydrotherapy helps a sluggish lymph system get going again, and that hot and cool packs, massage, acupuncture and ultrasound all have their place in a typical treatment regimen.

Watch eating, sleeping habits

"Eat a prudent diet," he told the patients present. "Carbohydrate-based, with lots of fruits and vegetables but light on meats."

Lapp has always told his patients to avoid sugar, caffeine, alcohol, Nutrasweet and tobacco, as well as dairy and wheat if they're particularly sensitive.

He also recommends a good-quality multivitamin, B-12, CoQ10, minerals and Omega 3 and 6 fatty acids.

"Get sleep, headache and myalgia issues under control," he recommended.

With kids, Lapp said good sleep hygiene is particularly important. Don't allow children to make their bed the center of their world: make it simply for sleep. Find another place for them to lie down when they're up out of bed--a recliner or sofa, for example. Help kids develop a bedtime routine--brushing their teeth, reading for a few minutes, perhaps taking proper medications an hour previously.

"Allow a 30- to 60-minute wind-down period before bedtime," he said.

For sleep problems in pediatric CFS, Lapp recommends Benadryl first, then Tylenol PM or Excedrin PM. If that doesn't help, 0.5 mg of Klonopin or 10 mg Doxepin usually work. Occasionally, with older children, he'll try Trazadone, Valium or Ativan.

For fatigue, Lapp uses SSRIs or dopamine agonists to take care of the low serotonin in the brain and serum of CFS patients.

Treatment for pain

For headache relief for children, he likes to first use cool packs at the front and back of the head, and then he'll try NSAIDs such as Tylenol. Only if those two do not work separately or concurrently, he'll try Diamox, calcium channel blockers or analgesic sedatives. In the worst of cases, he'll use Midrin or Imitrex.

For pain, he's careful to medicate only when absolutely necessary.

"Sometimes you can distract children from their pain, so try that first," Dr. Lapp said. "Cool packs are good. If those don't have any effect, use NSAIDs, then narcotic analgesics. Also try erithropoietin or epoetin alfa."

For kids with neurally mediated hypotension, he finds that water, salt tablets, Florinef, or beta blockers like Norpace CR can help with the dizzy spells and fainting. "Our studies are showing total body water is low in PWCs," he said. "It may be a renal deficit."

Dr. Lapp noted that it can be hard to differentiate between CFS and Attention Deficit Disorder, so he urged physicians and parents to make sure their patients and children were tested appropriately.

Psychosocial issues critical

But Lapp stressed that with kids, the psychosocial implications are doubly important.

"These kids may look healthy, and yet can be severely ill," he said. The effects of a chronic illness on a child or teen's self-perception can be enormous, he noted.

In a study of children and teens, Lapp found that 98% felt different than their peers in physical appearance, motility and vocation.

Sympathy and understanding from the health-care team and parents are very important for youngsters suffering from this illness, he said.

"Allow them to discuss their feelings," he encouraged, "and make sure you're communicating well with their teachers and school officials" about their schoolwork.

Remember that the Individuals with Disabilities Act provides for children with CFS: they can be considered under the part of the act that allows "other health-impaired" kids to be eligible for options

like having more time for assignments, tutors, waivers of physical activity and help with testing.

"The ultimate goal should be to get the kid back in school," Dr. Lapp noted. "I first try full-time with accommodations. Then we try part-time. Only in the worst cases do we try to school the child at home."

Panel discussion

A panel discussion followed, with Drs. Bell and Lapp joined by John F. Campion, MD, chief of the division of adolescent inpatient psychiatry at Lehigh Valley Hospital; Martha A. Lusser, MD, clinical associate professor of pediatrics at Pennsylvania State University College of Medicine in Hershey, Pa., and an adult and pediatric neurologist on staff at Lehigh Valley Hospital and St. Luke□ s Hospital; Karen F. Senft, MD, director of outpatient pediatric rehabilitation at Good Shepherd Rehabilitation Hospital; and John D. VanBrakle, MD, chairman of the department of pediatrics at Lehigh Valley Hospital.

When asked about prevalence, Dr. Bell said he believes doctors have seen "only the tip of the iceberg."

Dr. Lapp noted that the latest figures show that 200 per 100,000 people in the U.S. have CFS.

Dr. Poesnecker, a CFS specialist in Quakertown, Pa., said he found that many CFS patients first noticed symptoms related to low blood pressure. Dr. Bell said he sees lots of prior syncope in his pediatric patients.

A panelist remarked that Dr. Peter Rowe is trying to determine if those who suffer from syncope are more at risk for CFS in his studies at Johns Hopkins. However, while vasovagal syncope might cause fatigue up to 12 hours later, people with that illness can sleep and feel better the next day.

An audience member asked about melatonin to help PWCs sleep. Dr. Lapp recommended 1-6 mg, but noted that there have been no studies to determine a proper dosing for children.

Dr. Campion was asked if he thought CFS was "a primary psychiatric disorder."

He mentioned that in his practice, two children suffer from simple chronic fatigue: one is bipolar, he said, and the other has a school avoidance issue. Neither suffers from CFS then, noted Dr. Bell.

Another audience member asked about depression and CFS, and Dr. Lapp responded, "I deal with that as a separate issue. If appropriate, I urge you to send the child to a psychologist or psychiatrist."

It's not depression

When yet another person in the audience asked about the differences between CFS and "a coping problem," Drs. Bell and Lapp began a well-orchestrated rebuttal.

"There are distinct differences," began Dr. Bell. "CFS patients have a suppressed HPA axis, while the opposite is true in depression. CFS patients will have slow brain waves and large amounts of beta activity and a SPECT scan will show a marked decrease in blood flow to the brain. Ninety-six percent of CFS patients have NMH."

Dr. Lapp picked up the assault.

"In Australia, they're finding unique amino acid differences in CFS patients," he said. "For instance, serine is frequently decreased in CFS patients. They're also finding altered gut flora in CFS patients,

with (a much higher) percent of E. coli than is normal. Serine is a fairly common treatment in Australia."

Dr. Lapp continued:

"Dr. Mark Demitrack has shown that CFS patients show a marked decrease in cortisol, which results in the suppression of the HPA axis. The effects are profound hormonal changes and phase shifting - a diurnal shift in which patients find themselves falling to sleep later and later."

"There is a physiological basis to this illness," said Dr. Bell.

"Any depression doesn't cause sore throats, lymphodenapathy, fevers and cognitive problems of the kind we see," noted Dr. Lapp. "There's just no way to blow off all of the CFS symptoms to depression."

At this point, the audience got the picture, and asked if any of the physicians used stimulants in their CFS patients.

"Low doses of amphetamines can speed up the brain waves," Dr. Lapp said. "At the Cleveland Clinic, it was noticed that many CFS patients had ADD. I think you'll find that Ritalin is good for cognitive problems, low energy and low blood pressure."

Dr. Bell added, "The irony is that every primary care physician knows how to treat this. It's a difficult diagnosis to make; doctors would be much more comfortable with a diagnostic test."

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