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LifelineLetter

Living with home parenteral and/or enteral nutrition (HPEN)

Trace Element Requirements for Adults on Long-Term Parenteral Nutrition

Lyn Howard, MB, FRCP, FACP, Medical & Research Director, The Oley Foundation

The research upon which the conclusions in this article are based is discussed in depth in "Autopsy tissue trace elements in 8 long-term parenteral nutrition patients who received the current U.S. Food and Drug Administration formulation," Journal of Parenteral and Enteral Nutrition 31 (2007), 388–96. Tables 2 and 3 are reprinted from the JPEN article with permission.

Trace elements are minerals needed by the body to regulate metabolism (table 1). Like vitamins, they are required in very small amounts, and large amounts may be toxic. In the early years of parenteral nutrition therapy, trace minerals were largely ignored; but as we extended our reliance on this therapy from weeks to months, deficiency syndromes of zinc, copper, chromium, and selenium were reported.

The questions then became: how much of these trace elements should we add to parenteral solutions, and how can we monitor patients for adequacy or excess?

Setting a Standard

In 1979, following a research meeting of human

Table 1. The required trace elements and their metabolic functions

Element	Metabolic Function
Iron	Energy transfer by hemoglobin and cytochromes
Zinc	Growth, healing, immune function
Copper	Connective tissue formation and energy transfer
Manganese	Arginine, pyruvate, superoxide metabolism
Chromium	Part of insulin receptor
Selenium	Prevents peroxidation of reduced compounds such as glutathione

trace element experts, the American Medical Association (AMA) published recommendations for routine additions of zinc, copper, manganese, and chromium

Trace Elements, cont. pg. 2 ➤

California, Here We Come!

The site is selected for the 23rd Annual Oley Consumer/Clinician Conference. Mark your calendar and plan to join us June 26 to 30 at the Mission Valley Marriott in San Diego, California (www.sandiego-marriottmissionvalley.com).

Offering a relaxed atmosphere and all of the wonderful Marriott amenities (including a balcony in every room!), this setting is ideally situated in the heart of San Diego.



Southern California's popular attractions—historic old town, the Gaslamp Quarter District, Sea World, the famous San Diego Zoo—downtown, and a diverse selection of shopping and restaurants are all just a trolley ride away. And of course the main reason for joining us is to learn more about

Conference, cont. pg. 4 ➤



Aleah with her mom at the 2007 Oley conference.

A Teenager's Journey

Susan Begay

To a casual observer, thirteen-year-old Aleah Smith blends in effortlessly with all the other seventh-grade girls in the halls of Tri-West Middle School in Lizton, Indiana. Long blonde hair, big blue eyes, dressed in clothes that fit the age and the times. She's petite, to be sure, but not so small that she stands out from other girls her age who are on the dainty side.

Teenager, cont. pg. 6 ➤

Trace Elements, from pg. 1

to parenteral formulas. A few years later a recommendation for selenium was also added. These experts made it clear that they expected their recommendations to be redefined and updated as new research information became available.

The Food and Drug Administration (FDA) has a fundamental obligation to protect the population from harmful drug effects. The

FDA adopted the 1979 AMA recommendations for a parenteral multiple trace element (MTE) additive. This became the mandatory standard for any MTE commercial preparation used in the United States.

Outdated Standard

During the past thirty years, as predicted by the early scientists, new research information has led scientists to modify parenteral trace element recommendations. Table 2 shows the original 1979 AMA adult trace element guideline and the subsequent changes advised as new research data accumulated. The chief alterations were the much lower amounts of copper (upper level now one-third of 1979 amount) and manganese (upper level now one-eighth of 1979 amount).

Despite research data to support these changes, the FDA has not updated its recommended MTE formulation. Patients continue to receive the original 1979 formula unless their prescribing physicians order each trace

element separately, which adds significant cost and room for error. The FDA is unlikely to change its designated MTE formula unless there is clear evidence of harm to patients receiving the 1979 MTE formula!

The question therefore becomes: is there evidence of harm and should long-term parenteral nutrition patients be asking for routine trace element monitoring? The answer is probably "yes" to harm and "no" to routine monitoring.

Routine Monitoring

There are many pitfalls to routine clinical monitoring. First, trace element sampling and measurement requires a meticulous technique to avoid the risk of contamination leading to a misleading result. Second, the best test of nutrient adequacy is a measure of its biological function. If this function is normal, it indicates the nutrient is present in adequate amounts. Such a test is available for iron, iodine, and, in

Trace Elements, cont. pg. 8

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The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. For all others, the annual rate due each January is \$40.

The *LifelineLetter* is the bi-monthly newsletter of the Oley Foundation. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed with your health care provider prior to actual use. Correspondence can be sent to the Editor at the address above.

Table 2. Parenteral trace elements*

	Zinc** Mg	Copper† Mg	Manganese‡ mcg	Chromium ^Δ mcg	Selenium ^Δ mcg
Adult guidelines					
1979 AMA	2.5–4	0.5–1.5	150–800	10–15	—
1984 NY Academy of Medicine, AMA	2.5–4	0.3–0.5	400–800	10–20	50–60
1994 M. E. Shils	2.5–4	0.3–0.5	60–100	10–15	40–80
1998 A.S.P.E.N	2.5–5	0.3–0.5	60–100	10–15	—
2004 A.S.P.E.N	2.5–5	0.3–0.5	60–100	10–15	20–60
Amount received/day by Albany Medical Center patients	3 plus 3–5 mg/L enteric loss	1.4	700	14	85
Available commercial products					
<i>American Regent (1 mL)#</i>					
Multitrace [®] -4	1	0.4	100	4	—
Multitrace [®] -4 Concentrate	5	1	500	10	—
Multitrace [®] -5	1	0.4	100	4	20
Multitrace [®] -5 Concentrate	5	1	500	10	60
<i>Abbott/Hospira (5 mL)</i>					
4 Trace element	4	1	800	10	—

*Table reprinted from "Autopsy tissue trace elements in 8 long-term parenteral nutrition patients who received the current U.S. Food and Drug Administration formulation," *Journal of Parenteral and Enteral Nutrition* 31 (2007), 388–96, with permission.

** Increase with abnormal intestinal losses.

† Decrease or omit with increasing severity of jaundice.

Δ Decrease or omit with increasing renal dysfunction.

Single-entity trace elements are available.

Tube Talk

Thank you to everyone who sent material for the "Tube Talk" column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or E-mail Metzgel@mail.amc.edu. Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.



Device Crushes and Administers Meds

If grinding up meds is problematic for you, here's one alternative to a mortar and pestle. Known as the PillCrusher™, it is a syringe that allows the user to crush tablet medications, draw up water, and administer the medication — all with one device. The PillCrusher is available through Nurse Assist in Forth Worth, Texas (www.nurseassist.com). Call toll-free (800) 649-6800 and ask for item #3305. The price quoted in November 2007 was \$21 for a case of 30 syringes. Please note: the product was not available for purchase online.

More Advice for Granulation Tissue

We put Neosporin-Pain (special Neosporin formulation with pain medication in it; available at Walmart, etc.) on the granulation tissue around my daughter Charlotte's g-tube site with good results. The tissue shrank and she was much more comfortable.

—Lujean Bandur
Duquoin, IL

Capitol Hill Advocacy: March 9–10, 2008

Join Oley as we participate in the Digestive Disease National Coalition's effort to bring awareness of digestive diseases and related challenges to our elected officials in Washington, D.C. On March 9 there will be an orientation as well as legislation and policy update. March 10 we'll visit our representatives. This annual event brings together patients, health care providers, industry representatives, lawmakers, etc. to help attach a face and personal circumstance to the needs of people with digestive disorders. For more information stay tuned to www.oley.org or call (800) 776-6539.

Connect to the Oley Pipeline

Whether or not you choose to receive the newsletter electronically, please consider signing up to receive time-sensitive messages via e-mail. You'll get notices in a timelier manner than you would through the U.S. mail.

Oley news is also posted regularly on www.oley.org. Visit frequently!



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Meet Us in Chicago

Join Oley for a daylong regional conference at the Hyatt Regency Chicago on Saturday, February 9, 2008. It is a great chance to network with other consumers/families and top clinicians, and a relatively inexpensive, non-stop flight from many areas of the country. Sessions will be held in the morning and afternoon, with a midday break for lunch and exhibits. This educational program is provided to homePEN patients and their families at no cost. Tune in to www.oley.org for details about speakers and programs.

This conference is followed immediately by A.S.P.E.N.'s Clinical Nutrition Week, which will run through February 13, also at the Hyatt Regency. Please call (800) 776-6539 or e-mail swensek@mail.amc.edu to learn about opportunities to staff the Oley exhibit booth during this event. Staffing the booth gives you access to the A.S.P.E.N. exhibit hall where you can learn about the latest homePEN products and services.

Mom Seeks Advice

The mother of a thirteen-year-old boy with short bowel who is TPN dependent and has low bone density is looking to speak to anyone whose child is being treated for osteoporosis. You can contact the mom, Cheryl, directly at cayay@comcast.net or call the Oley office (800-776-OLEY) and we'll put you in touch.

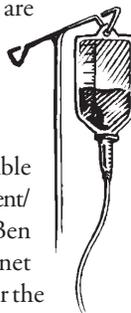
Equipment/Supply Exchange

Formula, tubing, and all sorts of miscellaneous items are listed in the Oley Foundation Equipment Exchange. If you need something or if you have something useful that someone else may need, the Exchange is there to serve you. The formula and supplies available change daily.

Full details about the program and a list of items available can be viewed at www.oley.org. Or contact the Oley Equipment/Supply Exchange Coordinator, Ben Hawkins, at benhawkins@fuse.net or 866-454-7351 (toll free) for the most up-to-date listing. Please call Ben between 9 a.m. and 9 p.m. EST.



Note: It is important to let Ben know whether or not you have taken the item(s) he has offered to you so they don't go to waste.



Giving Thanks

As an executive director, there's nothing more gratifying than knowing that your organization's efforts make a difference in the lives of those in your community. In the Oley community, member feedback, positive and negative (yes, we encourage this!), continues to guide us towards building stronger programs. Your efforts, as individuals, complement ours. Life has been good in 2007.

With a glance at 2008, however, we ask ourselves how we can improve. The answer is quite simple: reach more consumers!



Joan Bishop

It is your energy and enthusiasm that drives this effort. Responding positively, such as with willingness to staff an exhibit table at a conference in your area, has an enormous impact on our ability to reach others. Professionals learn more about Oley via your conversations. Others learn about Oley because you share your newsletters and Keep Me Safe posters—and they join!

In typical Oley style, we show our appreciation by asking you to do more. Outreach, outreach, and more outreach! We must reach those who are not connected to Oley. Please... if you have a story to share, an anniversary to celebrate, or just want to talk about life as an Oley member, do not hesitate to contact us at (800) 776-6539 or bishopj@mail.amc.edu. We'll work with you!

Of course, what would a note from me be without a plea for financial support? The annual appeal drive is under way and, while we know that many organizations are competing for your philanthropic dollars, we hope that you will send what you can, when you can. In return we pledge to do our best to see that your donation stretches as far as possible.

Oley enters its twenty-fifth year in 2008. Powered by your support and willingness to help, we are building an organization with great potential.

We thank you for everything and wish you the happiest of all holidays!

— Joan Bishop
Executive Director
The Oley Foundation

Conference, from pg. 1

the therapy that sustains you or a loved one. We promise to treat you to a host of different topics to enhance your understanding. Stay tuned to www.oley.org or call (800) 776-6539 for updates.

Note: We invite you to send along suggestions regarding topics you'd like to see covered and/or recommendations for speakers. Send your ideas to Joan Bishop at bishopj@mail.amc.edu or call her at (800) 776-6539 to discuss them. ¶

Ongoing Research Trials

Genetic Study of Hirschsprung Disease

Hirschsprung disease (HD) is a complex genetic puzzle that researchers are still trying to piece together. The staff at Johns Hopkins University's laboratory, led by Dr. Aravinda Chakravarti, has been investigating the genetic basis of HD for nearly fifteen years. The team's current focus is on the major gene implicated in HD, called RET, and on identifying additional "modifying" genes that influence whether a particular individual develops HD.

Participants for the study are actively being sought. Study volunteers will be asked to:

- complete a medical/family history questionnaire;
- submit blood samples from the individual(s) affected with Hirschsprung disease and his or her parents.

The study may lead to a better understanding of the genetics of HD and, further down the road, improved diagnosis, treatment, and genetic counseling.

If you are interested, a kit containing all the materials necessary to participate will be sent to you. There will be no cost to you.

If you have any questions or would like more information about participating, please contact the study coordinator, Julie Muskett, at (410) 502-7541 or hirschsprung@igm.jhmi.edu.

Study of Hyperemesis Gravidarum

Hyperemesis gravidarum is severe nausea and vomiting of pregnancy requiring IV hydration and/or nutritional support. This is a study to identify epidemiologic and genetic factors involved in hyperemesis gravidarum.

There is no cost to participants or travel needed to participate in this study. Participants will be asked to:

- sign a consent form;
- answer a risk factor and outcomes survey;
- submit a saliva sample for DNA analysis; and
- identify an unaffected friend with at least 2 pregnancies that went beyond 27 weeks to participate in the study as a control.

If you have been diagnosed with hyperemesis gravidarum and you are interested in participating, please e-mail Dr. Marlena Fejzo at nypstudy@usc.edu to determine eligibility.

This study is run by Dr. Marlena S. Fejzo and Dr. T. M. Goodwin at the University of Southern California, Los Angeles, is supported in part by the Intramural Research Program of the National Institute of Child Health and Human Development, National Institute of Health, Department of Health and Human Services, and has been approved by the USC Institutional Review Board HS-06-00056.

Both of the research studies listed have been deemed appropriate for homePEN consumers/caregivers by the Oley Research Committee; however, *the Oley Foundation strongly encourages anyone considering participating in medical research to discuss the issue with their managing physician before signing up.*

More information on these studies is available by calling (800) 776-OLEY or visiting our Web site at www.oley.org. Clinicians interested in having their study listed should complete the form at www.oley.org or fax the same information to (518) 262-5528.

Remembering Bruce Grefrath

Susan Parker

Bruce Grefrath, former Oley Regional Coordinator for the Washington, D.C., area, passed away November 13, 2007. From the very beginning of his sojourn, forty years ago, Bruce was a tenacious fighter—as are all the members of Oley. Bruce started on parenteral nutrition in 1984. He had only two sepsis incidents up until this past year, when he fought off three occurrences while dealing with terminal cancer of a duct in the liver.



Bruce Grefrath

Bruce was a charter member of the Oley Foundation. As a group, we started out meeting at a picnic, which was followed by a full-blown conference in Saratoga Springs the following year. Bruce used his expertise as a former lobbyist on Capitol Hill to serve as a liaison between the Oley Foundation and members of Congress. He served on the Board of Trustees and participated in the Lifeline Advisory Group.

People called Bruce from all over the country for advice on how to keep their health coverage. After having gone through a few incidents of this nature himself, he became a great asset to others as he researched many possible solutions to this horrendous problem. He reported on the politics of health coverage in the *LifelineLetter*.

Bruce was a man for all seasons. He had many interests, including white-water canoeing, bird watching, forestry issues, property rights, and history. He wrote a historical article for the *Washington Times*, and was also writing a cultural and scientific book on Skyline Drive.

Bruce was a great cook, too! He entertained people at our home constantly. He had the pleasure of serving a wonderful meal to Oley's Joan Bishop and Dr. Howard.

Bruce had an impact on everyone he met. The Oley community will miss him greatly.

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Improving Life on Nutrition Support

Teenager, from pg. 1

Appearances can be deceiving, though. In Aleah's case, they don't even come close to revealing the truth about the inner workings of her lean, lithe body, which have challenged her from the minute she was born on August 9, 1994.

Short Bowel at Birth

During Tara Smith's pregnancy with her firstborn child, nothing hinted at anything amiss until a routine ultrasound at twenty-nine weeks gestation showed a bowel obstruction in tiny Aleah. Tara and her husband, Kevin, who were living in Fairfield, California, at the time, wouldn't know the extent of Aleah's health issues until she was born, five weeks early. Aleah underwent her first surgery when she was only fourteen hours old. Surgeons removed a cyst from Aleah's left abdomen and discovered that she had only 25 cm. of small intestine. The diagnosis: short bowel syndrome.

Over the next three weeks, it became evident that Aleah's stomach was not emptying at all. She vomited everything she was fed. It was then that the enormity of her condition began to sink in, as specialists laid out for the worried parents two stark options: Aleah could be PN-dependent all of her life, or doctors



Aleah (second from left) at school with her sister and friends.

could undertake an extensive (and very risky) surgery to attempt to resect her GI tract. Doctors were unsure if the surgery would be successful and tried to prepare Tara and Kevin for the worst. They had to face the possibility of losing their little daughter only four months after Tara had lost her father to a motorcycle accident.

Defying Odds

Aleah survived the surgery and began a long journey of defying most of the medical odds and predictions that had been laid before her parents. In thirteen years, she has endured fourteen surgeries and so many hospitalizations that her mother can't remember them all without consulting the thick volumes of medical records and notes she's meticulously accumulated since 1994.

Today, there are no remaining visual clues to suggest that Aleah was once a very sick child who endured many hardships and much pain before reaching this seventh-grade school year, described by Aleah as her "best ever." She has been off PN feedings since the year 2000 and had her g-tube removed and stoma closed in 2005.

Early School Challenges

Things were much harder in the past. Aleah describes how she moved to her current home in Pittsboro, Indiana, with her parents and younger twin sisters, Sky and Keely, in 2001, just before she started first grade. "I was new at school. Kids stared at me and the backpack I wore [which contained her feeding pump]. My pump would start alarming right in the middle of class. It was very embarrassing."

The school nurse had spoken to the class that year and explained Aleah's special health needs to her classmates, which Aleah believes made the situation more tolerable than it might have otherwise been. First graders, by nature, are inquisitive and tend to blurt out their every observation without thinking, but they're still warmly accepting and nonjudgmental at that age.

Still, trying to fit in with your classmates is hard when you have to visit the school nurse every day to have your feeding pump bag refilled. Aleah couldn't hang upside down on the monkey bars with the other kids at recess because her pump alarm would blare. Her participation in gym class was often limited, depending on the types of activities the class was doing that day.

All things considered, Aleah says she remembers those early grades as going pretty smoothly, except for the frequent absences when she wasn't feeling well and had doctor appointments and several hospitalizations.

"At the end of one of my school years, my parents received a nasty letter from the school corporation because I'd missed twenty days of school that year, but Mom and Dad were jumping for joy because I'd only missed twenty days that year!" Aleah smiled. In past years, she'd missed months.

By fourth grade, things became tougher for Aleah. She felt much shorter than her classmates. She became more self-conscious about her medical condition. Her Mic-key button showed through her clothes. Her Bard button leaked and ruined her favorite green-and-white shirt. "Yes, stomach acid ruins clothes," she says. She grins as she says this now, but back then, she found it mortifying.

The Worst to the Best

Nothing she'd experienced from first through fourth grade, however, prepared her for fifth grade. Her sweet smile fades and she casts her eyes downward when she revisits the year she calls her "worst ever." Kids began teasing and mocking her. Some girls passed around notebooks with harsh comments written about her and, worse yet, encouraged others to write about her. A boy made up a game called "Aleah's Germs."

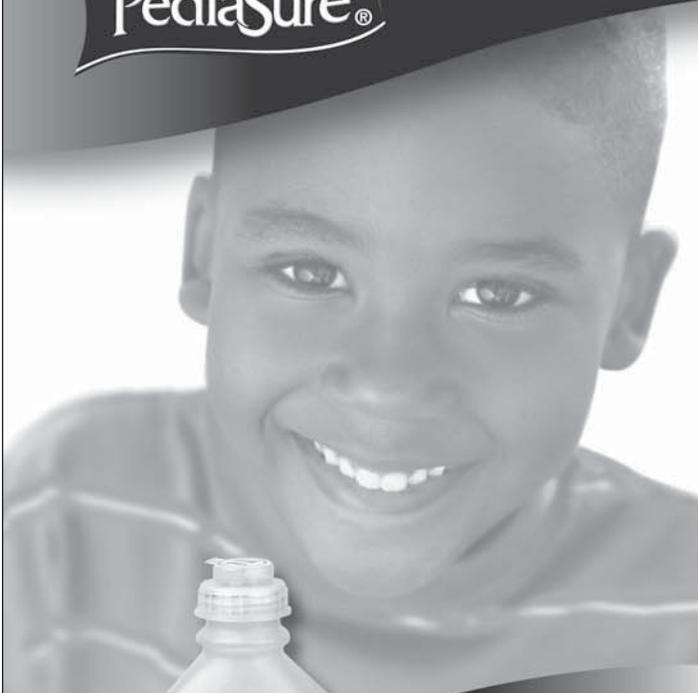
With the help and support of a handful of good friends and the always-present guidance from her parents, Aleah survived fifth grade and moved on to middle school, where things improved dramatically. She made new friends. She joined the band and participated in the school play. Old bullies moved on and left her alone. She experienced a new sense of freedom in moving from class to class seven periods each day, no longer under the constant scrutiny of any one set group of kids.

When asked about the challenges—both social and physical—that face her today, Aleah answers without hesitation, "Gym class." In seventh grade, the girls have to change their clothes in locker rooms, in front of each other, and Aleah feels their eyes upon her at times, perhaps surveying all the scars she bears from her multiple surgeries. But it's a different kind of staring now. She thinks it's mostly out of curiosity and not hurtful or ostracizing. Some even ask her questions, but she prefers not to talk about it too much—not because she's ashamed or embarrassed, but because it's just such a long story to tell. Seventh graders have places to go, people to see. Long stories about past medical woes aren't part of the daily agenda.

Teenager, cont. pg. 9

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LITHO IN USA

Trace Elements, from pg. 2

research settings, for selenium. For zinc, copper, chromium, and manganese, clinical tests of functional adequacy are not available.

Clinicians often turn to assessing trace elements by plasma or serum levels. Measuring these levels can be helpful in persons not receiving trace element supplements. In persons who are receiving trace element supplements, careful balance studies have shown no correlation of plasma or serum levels with body stores or adequate amounts in the tissue. Under these circumstances a blood level reflects the amount infused, not the amount needed. Furthermore, it is not known how long a specific trace element should be withheld to obtain an interpretable measurement.

This problem is compounded by the fact that many parenteral components are contaminated with varying amounts of trace elements. These nonprescribed sources can provide 10 to 100 percent of the daily requirement. Manganese and chromium are particularly common contaminants.

Because of these drawbacks, the question of trace element adequacy versus toxicity is most likely to be resolved in a research setting, rather than through routine clinical monitoring. Indeed, it was complex research balance studies that led to recommendations for a mild reduction in zinc and a significant reduction in copper from the 1979 guidelines.

Evidence of Harm

Manganese levels were known to be high but clinical toxicity was not documented until Fell and Reynolds described a neurological syndrome in children of irritability and Parkinsonian-like tremors which correlated with abnormal brain MRI findings.¹ Both the symptoms and the MRI abnormalities slowly disappeared after manganese supplements were stopped. Interestingly the children's liver function also improved as their manganese levels subsided, suggesting toxic manganese levels may contribute to parenteral nutrition liver dysfunction. Japanese studies have recently shown that 55 mcg/day of manganese is all that is needed to sustain normal blood levels. This may in fact be supplied by parenteral contaminants, making a routine parenteral manganese addition unnecessary.

In the Albany Medical College home parenteral nutrition (HPN) program we studied the cumulative effect of the 1979 MTE

formulation in tissues obtained at autopsy. Long-term HPN consumers were asked to consider donating their bodies to this research if and when they died. Over ten years eight people died and their tissues were carefully sampled and sent to the Trace Element Unit of the Royal Infirmary, Glasgow, Scotland. Iron, zinc, copper, manganese, chromium, and selenium were measured by inductively coupled plasma methodology in heart, muscle, liver, and kidney tissues. These results were compared to tissue levels in forty-five control subjects who died without a chronic gastrointestinal disorder.

The eight Albany patients had lived on HPN for an average of fourteen years (range two to twenty-one years), and their HPN had contained the 1979 MTE formula (table 2). Their tissues showed normal amounts of iron and selenium, mild elevations of hepatic zinc, and major elevations of hepatic copper, manganese, and chromium. In four of the eight patients, hepatic copper reached the toxic levels characteristic of Wilson's disease. This is a rare genetic syndrome of abnormal copper storage which leads to severe neurologic and hepatic damage.

While no clear-cut neurological syndrome was recognized in these patients, two died from liver failure. As their bilirubin levels started to rise, copper and manganese additions were discontinued in their parenteral solutions. This modification was obviously too late to change their hepatic copper and manganese accumulation. The unanswered question is: did excessive copper and manganese contribute to their liver failure or did they have another

cause of liver disease that led to copper and manganese buildup, since these two elements are normally excreted in bile? Whatever the order of events, our tissue results strongly support the need for the FDA to revisit adult parenteral trace element guidelines for copper and manganese.

The high chromium levels are less of a concern because chromium toxicity has only been described in steel welders exposed to airborne chromium (Cr⁶ valency). Chromium is believed to be biologically active in an organic form as part of the insulin receptor. The measurement technique we used cannot distinguish the particular chemical form of this element. It seems likely that the excess chromium we measured was in a non-biologically active form. True assessment of chromium adequacy requires measurement of insulin sensitivity.

Recommendations

Where does this research data leave us? It strongly points to a risk of copper and manganese toxicity with the current FDA formulation. Clearly the FDA needs to revise its parenteral trace element recommendation. Traditionally this occurs when relevant professional organizations hold a high-level consensus conference at which all new scientific data are reviewed. Unfortunately, many national nutrition organizations consider parenteral trace elements too small a topic to warrant this consensus approach.

Consumers (long-term HPN patients) and their supporting professionals may have to band together and threaten to sue the FDA for a

Trace Elements, cont. pg. 10

Table 3. The multiple trace element formula recommended by the authors for adults on long-term parenteral nutrition*

Element	Amount/day	Comment
Zinc	3-6 mg	2 mg/kg of enteral loss for a total of 6-12 mg/day
Copper	0.3-0.5 mg	Discontinue when serum aminotransferases and alkaline phosphatase > 2x normal. Check serum Cu levels every 6-12 mo thereafter.
Manganese	30-60 mcg	Discontinue when serum aminotransferases and alkaline phosphatase > 2 x normal. Check serum Mn levels every 6-12 mo thereafter.
Chromium	5-10 mcg	Check HbA1C every 6 mo
Selenium	60-100 mcg	Higher dose in adults < 40 y.o.

*Table reprinted from "Autopsy tissue trace elements in 8 long-term parenteral nutrition patients who received the current U.S. Food and Drug Administration formulation," *Journal of Parenteral and Enteral Nutrition* 31 (2007), 388-96, with permission.

Teenager, from pg. 7

As great as seventh grade has been so far, mini issues continue to pop up. Because the muscles on the backs of her legs are very tight, she has trouble doing leg lifts and stretching exercises in gym class. Sometimes girls have ordered, "Aleah, get your leg up higher!" But she stands up for herself more and more these days, something she found very difficult to do when she was younger. When someone asks her why she gets to use the school's elevator and the others don't, she smiles and says simply, "Because I'm allowed to."

Tired, But Happy

Other trials currently facing Aleah are the almost-continual body aches she's experienced over the past year. Physical competitions are very hard for her. When she misses school these days, it's much more difficult to make up the work, she says. She sometimes has to leave events early, such as her best friend's sleepover, because she's tired or achy. She missed her first middle school dance entirely. Things that help

Aleah has learned
over the years to listen
carefully to what her
body is telling her.

her feel better are heating pads, hot baths, and lots of sleep.

Aleah has learned over the years to listen carefully to what her body is telling her. Her advice to other kids: "When you're tired. . .sleep!"

The hardest aspect of the young teen's life right now medically is the need to eat every one to two hours, which she describes as tiresome and "not as fun as my friends think it would be." She says her body is trying to grow but seems to be on "overload." She stands just one-half inch shy of five feet tall and weighs eighty-five pounds, and while she would like to be taller, she concedes that she's happy with herself as she is.

Strength Through Sharing

The Smiths credit the Oley Foundation with serving as a life preserver for them all these years. Tara began serving as a Regional Coordinator three years ago. Aleah shares that the great thing about attending the yearly conferences is that everyone there "understands." No explanations needed. If an ostomy bag leaks at an Oley conference, no one gives it a second glance.

She wishes that there had been some method of daily communication available between Oley kids when she was younger. She's quick to credit her friends with filling that void, though, and says she's come to the realization that everyone has his or her own cross to bear. One good friend was diagnosed with juvenile diabetes. Another has a younger sister who has seizures.

Looking on the Bright Side

Although serious medical concerns are less frequent and farther between these days, they still occur. On November 5, 2007, Aleah had surgery at Riley Children's Hospital in Indianapolis to remove a bronchogenic cyst from her diaphragm behind the left lung and heart. Before the surgery she seemed unfazed and instead concentrated on her hope that the surgery would relieve her body aches and pains.

Aleah remembers how she used to ask, "Why me?" when she was younger. Not anymore. She believes her health issues have made

Teenager, cont. pg. 10 ◀



Have Home PN. Will travel.

Our consumers don't have to stay put because of their treatment. At least that's what Jerry Fickle believes. He's been on Home PN more than 25 years. In that time he's been on an Alaskan cruise, to wherever Purdue University plays in a bowl game, to Florida, and on bus trips with seniors groups. He plays golf and rides a Jet Ski when he can find the time. Jerry doesn't see why he can't do what he wants. And Coram encourages him, working with him to make it all possible. We got him started, and we'll be there for the long run.



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&
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The following list represents everyone who contributed between October 23 and November 26, 2007. We also want to thank all of those who are not listed below, yet have supported the Foundation by donating gifts earlier this fiscal year or have volunteered their time and talents.

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Teenager, from pg. 9

her kinder and more compassionate to others. She feels fortunate that she is no longer PN-dependent or on g-tube feedings. She beat the odds and defied the grim predictions made after her birth, a happy outcome she attributes to "a little luck, a lot of prayers, and my great parents."

When asked the hypothetical question, "Would you undo all this if you could?" she pauses a long time and finally answers with a half smile, "I don't know. I've lived with it so long. It's just who I am." ¶

—Susan Begay is a freelance writer and a friend of the Smith family.

Trace Elements, from pg. 8

medication change. The threat of a class action suit has produced a rapid FDA response in the past. (Editor's note: Micronutrients—vitamin and mineral additives—are being strongly considered as a topic for the 2009 A.S.P.E.N. research workshop. Stay tuned to www.oley.org for updates.)

Meanwhile, adult HPNers need to request a trace element formula that approaches the newer scientific recommendations. Table 3 summarizes what we now prescribe for the Albany Medical Center HPN consumers. It is made from one mL of Multitrace®-4 (American Regent, Inc.; see table 2 on page 2) with added zinc and selenium. ¶

¹ Fell, J.M., Reynolds, A.P., Meadows, N., et al. "Manganese toxicity in children receiving long term parenteral nutrition." *Lancet* 347 (1996), 1218–21; and Reynolds, N., Blumsohn, A., Baxter, J.P., Houston, G., Pennington, C.R. "Manganese requirement and toxicity in patients on home parenteral nutrition." *Clinical Nutrition* 17 (1998), 227–30.

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Oley Horizon Society

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at 800-776-OLEY.

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Entry Qualifications

1. The paper must have been presented in the calendar year prior to the Oley summer conference. (Eg. the 2008 Oley conference will consider papers as early as January 2007).
2. The author must apply for the annual award to the Oley Foundation by March 1. The check will be presented to the principal author at Oley's summer conference. \$1,000 of each prize will be in the form of a travel credit to bring recipients to the Oley conference to discuss their research.
3. The paper will not be reprinted (just the title will be acknowledged) but must have been accepted for poster presentation, stand-up presentation or publication by a respected, relevant professional association, such as ASPEN, ESPEN, INS, AGA, etc.



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Toll-Free Numbers Available to US and Canadian Consumers!

The Oley Foundation is able to offer its toll-free lines to consumers in the United States and Canada. Two toll-free numbers are circulated to experienced homePEN consumers on a monthly basis. The goal is to make speaking with fellow lifeliners more affordable, and to provide Oley's Regional Coordinators with a better grasp of their region's needs.

Advice given by volunteer coordinators represents the experience of that individual and should not imply endorsement by the Oley Foundation.

Due to the expense, a per-minute fee charged to Oley, we ask that you limit your conversations to 30 minutes.

The schedule of toll-free numbers and volunteer coordinators is updated in each LifelineLetter, and posted at www.oley.org. Comments? Call (800) 776-OLEY.

JAN. '08

Marilyn Sobiech
Brainerd, MN
(888) 610-3008 CST

Marilyn had been on PN for 9 years due to scleroderma with a lot of GI involvement. She has been off for the last 1½ years. She stays active with her 3 grandchildren, traveling, volunteering, and book and quilting clubs. She has experience with managing pain and fatigue. She also has experience with domestic and international travel, as well as camping and cruises.

Dave Helgeson
Vancouver, WA
(888) 650-3290 PST

A psychologist, Dave consults with public mental health systems. He began HEN via a j-tube after complications from Barrette's disease in 1997. In 2004, PN was added to his regimen due to malabsorption and chronic weight loss. He is happy to share what he has learned to save others from the same pitfalls.

FEB. '08

Zachary Colton
Ontario, Canada
(888) 610-3008 EST

Zac is on HPN due to mitochondrial disease and pseudo obstruction. He has had 3 major bowel surgeries. He has also been on HEN until recently. He loves running and is looking forward to attending college next year to study politics.

Joan Medwar
Sharon, MA
(888) 650-3290 EST

Joan and her son, Michael, have had Crohn's disease for over thirty years. She also has an ileostomy and celiac disease. Joan's other son, Greg is profoundly mentally challenged, has dysphagia and requires total care. Crafts and gardening help her cope with daily pressures. She believes in seeking aid through family and friends, support groups, government services, and psychological counseling.

MAR. '08

Davi & Steve Cohen
Crofton, MD
(888) 610-3008 EST

Davi has been on TPN for 20+ years due to short bowel syndrome resulting from a car accident. She has experience with port-a-caths in subclavian and femoral sites. Davi and Steve have been active at Oley, NAVAN, and ASPEN meetings and are willing to discuss the medical, logistical, and emotional aspects of long-term IV therapy.

Rose & Alicia Hoelle
Gibbstown, NJ
(888) 650-3290 EST

Alicia (22 y.o.) has been on HPN since birth due to hypoganglionis/NID. She has Crohn's disease too. Alicia is attending college to become a child life specialist. She has enjoyed camp, sports, and other activities. Her mother, Rose, is an LPN and experienced caregiver with a great sense of humor. Their favorite topics are advocacy, school accommodation, transitioning issues and dealing with long-term HPN.

LifelineLetter

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