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Importance of Positive Support

by *Diane Cameron*

Supportive family, friends, doctors and nurses are helpful and many times essential in dealing with chronic illness! During our close family's gathering around a table, my brother and his wife showed us plans for the new townhouse they felt they needed to buy. The new townhouse was necessary since he could no longer manage the incline of the driveway, maintenance, or the stairs in their soon-to-be former home.

As often happens, there was a long period before he was properly diagnosed. Unfortunately since that time, the illness progressed and more damage was done to his lungs. He has been diagnosed after struggling with recent illnesses with Alpha -1 antitrypsin deficiency ZZ. At his first appointment with a pulmonologist, he was immediately placed on oxygen. My brother was selective about oxygen use during working hours. He knew it would negatively affect the way employees and business associates would view his ability to continue as Controller/Treasurer of his company. Because his job was a further threat to his health, it ultimately became necessary for him to terminate his employment after almost 22 years!

They proceeded to tell us that Alpha-1 is a genetic disease and that the rest of the family should be confidentially tested. When I was tested, the results were positive for Alpha -1 antitrypsin deficiency ZZ also! I originally put the test results on the back burner. I was teaching full time and my life was busy. It became apparent that I was having difficulty climbing flights of stairs, walking up inclines, and combining walking and talking. I decided that this was because of the weight I was carrying. I prayed that nobody would see me on the landings panting for breath!

The following year I decided to have my protein level checked. I discovered that it was very low. Retired and armed with this information, I finally saw a pulmonologist and provided him with the information I had. I was frightened and concerned about confidentiality and medical records. I realized that "turtling" was not an option ("turtling" is refusing to deal with circumstances that need to be confronted).

My pulmonologist said I was an excellent candidate for augmentation therapy. However, this therapy could not repair

the damage already done to my lungs, but possibly it could maintain my current status. He felt I had emphysema for about nine years even though I had never smoked. I began weekly augmentation therapy one year ago soon after starting retirement.

My brother has had such positive support from his wife and their adult children. Fortunately, his wife is a nurse and is able to give him his infusions flexibly. His immediate family have all eagerly attended Alpha-1 conferences with him and pursued relevant education for themselves and others. His family has worked on a genetic family tree feeling that it will be valuable to future generations.

I don't have quite that level of support from immediate family other than my brother's family. That is partially because they don't observe me to be as ill as my precious brother. At this point, I am one of the blessed Alphas! Our parents have never quite known what to make of this. It wasn't a consideration in the 1940s when they were married. Even if we could, we wouldn't change our parents or other relatives. They have been incredible models for our family. Our sister is confused as to why she doesn't have Alpha-1 as she tested to be a carrier. Some of our relatives have refused to be tested or learn anything about this genetic disease.

I have learned that many with Alpha-1 have very sad scenarios in relation to family and friends. Fortunately, I have had contact with Alpha-1 advocates. They have provided me with information, education and the opportunity to attend the Alpha-1 Foundation Conference in St. Louis. I am looking forward to attending the annual Alpha-1 Association conference in San Francisco. I have not been able to locate an Alpha-1 Support Group in my area. Consequently, I have an interest in starting one. So many people have never heard of this chronic disease, surprisingly including many working in medical fields.

I have no anger, self-pity, or bitterness about having the disease. My heart breaks for my younger brother, who is more seriously ill at this point. He has had to discontinue working at a young age. For my brother, it took so long to get his diagnosis that additional damage occurred. It was exhausting just getting ready for work in the morning. Daily, he had a long commute, long work day, work travel required and a long return commute.

I treadmill at least three miles three times a week and "grammy-sit" my grandchildren. I count my blessings for the support I have. I understand that many people with Alpha-1 experience more negative journeys. Bad things do happen to good people, but I know that God is in control. I'll live one day at a time to the fullest with a positive attitude!

Alpha-1 Advocacy Alliance

"Our mission is to improve the health and well being of those affected by Alpha-1 through support to patients, educating healthcare professionals, and advancing public policy for the Alpha-1 Community."

Kamada Presents New Data on Its Alpha-1

Antitrypsin at the American Thoracic Society Annual Meeting

Kamada, a bio-pharmaceutical company engaged in the development, manufacturing and marketing of specialty life-saving therapeutics, announced that new, positive clinical data on its lead candidate, alpha-1 antitrypsin (“AAT”), was presented at the annual congress of the American Thoracic Society (“ATS”), May 15–20, in San Diego, California.

“The results presented at ATS demonstrate the efficacy and safety of our intravenous and inhaled versions of alpha-1 antitrypsin in respiratory disease,” said David Tsur, Chief Executive Officer of Kamada. “Pending regulatory processes, we hope to have our intravenous product in the US market during the course of next year. We are also very excited about the prospects for our inhaled version of alpha-1 antitrypsin in cystic fibrosis, and other respiratory disorders, and look forward to continuing its development.”

Pivotal Phase II/III Study in AAT Deficiency

Robert Sandhaus, Professor of Medicine, Director Alpha-1 Program, National Jewish Health, Denver Co. presented final data from Kamada’s pivotal study, a randomized, double blind, partial cross over study that explored Kamada’s proprietary, liquid, ready to use, intravenous AAT (“Kamada-AAT”) in patients with AAT deficiency. Forty-nine patients were randomized 2:1 to receive 60mg/kg Kamada-AAT or an equivalent intravenous comparator product, on a weekly basis, for 12 weeks. After the first 12 week period all patients were dosed with Kamada-AAT for a further 12 weeks. The study was designed to show non-inferiority of Kamada-AAT to comparator AAT. The results of this study support the primary endpoint. Adverse events considered related to the study drug were similar to those reported for currently marketed AAT products.

Phase II Proof-of-Concept Study in Cystic Fibrosis

Eitan Kerem, Professor of Pediatrics, Hadassah Medical Center, Mt. Scopus, Jerusalem, presented final data from Kamada’s Phase II, randomized, double blind, study that examined efficacy and safety of an inhaled version of Kamada’s AAT (“Inhaled-AAT”) versus placebo. Twenty-one patients were randomized 2:1 to receive 80mg Inhaled-AAT or placebo, once-daily, for 28 days. The data showed efficacy, as measured by a reduction in sputum neutrophil elastase and neutrophil count in patients treated with Inhaled-AAT. There were no serious adverse events reported in this study and the only adverse event reported, that was possibly related to study drug, was a sense of dry mouth (n=1). The results from this proof-of-concept study show that AAT administered via the inhaled route appears safe and biologically effective. Its impact on clinical endpoints, including measures of lung function, will be the subject of future studies.

Additional Analysis

Mark Brantly, Professor of Medicine, Molecular Genetics and Microbiology, University of Florida School of Medicine and Alpha One Foundation Research Professor, independently

presented data at ATS in a poster entitled, “Intravenous Augmentation with Kamada API Binds to Free Lung NE in Alpha-1 Antitrypsin Deficient Individuals with Lung Disease”, which included an analysis of bronchoalveolar lavage (BAL) data from sixteen patients in the pivotal trial. Patients who received Kamada-AAT showed a >10 fold increase in AAT concentration in the epithelial lining fluid (“ELF”) after 12 weeks of augmentation therapy and a significant increase in AAT-neutrophil elastase complexes. These data confirm that Kamada-AAT reaches the lower respiratory tract and binds to free neutrophil elastase in the ELF.

Shop at our Website



The A-1A Alliance Shoppe is located at <http://www.alpha1advocacy.org/frdonation.html>. While you are shopping for a T-shirt (design shown on the left), be sure to check out the other items offered as fund-raisers.

Also remember, when shopping online for ordinary items, be sure to go to the A1AA website and use the www.IGive.com and Giveline.com links to find those stores that give percentage (up to 25%) of your purchase dollars to your designated nonprofit organization. Also read about ordering magazine subscriptions through the A1AA website and save lots of money plus a possible free ticket for a movie.



Of course, our little buddy Alphapotamus can be purchased, too. Be sure to click on “full details here” and learn how Alphapotamus cheers up our little Alphas when they’re in the hospital. Any purchase on the A1AA Shoppe site helps the Alpha-1 Advo-

cacy Alliance continue to fulfill its mission “to advocate for all individuals affected by Alpha-1 Antitrypsin Deficiency (Alpha-1) through programs and services of personal advocacy, education, support and public policy in order to improve all aspects of their lives.”

If you’re not a member of the A1AA, please join. It’s a free membership and you’ll get updates about A1AA programs, personal support, plus a copy of the bi-monthly newsletter. To join, go to <http://www.alpha1advocacy.org/membership.html>. Thank you for your continued support and stay tuned for more announcements from the A1AA.

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Over 50,000 People Screened for AATD through Baxter-sponsored Effort

from the Alpha1Health.com Newsroom

Baxter International Inc. has helped screen more than 50,000 people for alpha1-antitrypsin deficiency (AATD), making it an industry leader in awareness and early diagnosis. Through the company's screening and prevalence study and provision of complimentary test kits to physicians for patient testing, more than 385 individuals have been identified since the program's inception in 2004.

In addition to deficient patients, Baxter has also helped identify more than 5,100 carriers of AATD, or 10 percent of those tested, through this program. Carriers of AATD have a lower-than-normal serum level of AAT and phenotyping shows that they carry one altered gene. The ATS/ERS standards suggest that these individuals may be more susceptible to the damaging effects of smoking and occupational/environmental pollutants than other individuals with normal levels of

AAT. This knowledge has helped physicians advise these individuals to stop smoking and implement other good health practices, including adhering to a good nutrition and exercise program and undergoing regular health exams. It also provides an opportunity for discussion of the genetics of this deficiency and to encourage patients to share this information with family members.

CSL and Talecris Terminate Merger Agreement in Face of FTC Opposition

In a June 8, 2009 letter, Peter Turner, president of CSL Limited, announced that CSL and Talecris mutually agreed to terminate their merger agreement. In the letter Turner explained that entering into a protracted litigation process with the U.S. Federal Trade Commission (FTC), given its substantial costs and the lengthy distraction of CSL management and staff, would not be in the best interests of its stakeholders.

Australian vaccines and blood products developer CSL Ltd. managing director Brian McNamee had met with FTC commissioners in Washington on May 22 to discuss the acquisition. He put forward pro-competitive arguments of CSL's case, including significant efficiencies and benefits to consumers resulting from the deal, presented potential remedies which may enable approval, and discussed the consideration of the case by FTC staff. However, CSL was informed during the meeting that the FTC staff, after reviewing CSL's case and remedy proposals, recommended that the commissioners initiate legal action in the U.S. District Court to block the transaction.

CSL had announced in August 2008 that it had signed an agreement to acquire Talecris. CSL had said the acquisition would be highly complementary to its existing business, giving it additional scale, breadth of products and expanded geographical presence in the global plasma products market. CSL estimated that profit improvement initiatives would generate benefits of about \$225 million per annum.



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**For Information Call: 540-948-6777 or Toll Free:
1-866-FOR-A1AA;**

**Fax: 540-948-6763
PO BOX 202**

**(1-866-367-2122)
Wolfstown, VA 22748**

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Talecris Biotherapeutics Wins Strategic Patient Adherence Awards

Pharm Exec was proud to partner this year with CBI on the eighth annual Forum on Patient Compliance, Adherence & Persistence. One of the highlights of the event is the presentation of the Strategic Patient Adherence Awards, which honor pharma-based programs to improve compliance.

For best integrated program, Talecris Biotherapeutics won the award for its health management program for patients with Alpha-1 Antitrypsin Deficiency, an extremely rare hereditary condition leading to chronic obstructive pulmonary disease. The program is noteworthy both for its remarkable success rate and for its use of a not-for-profit patient support group to provide extensive peer counseling.

Phone Home on Us

To sign up for the program cosponsored by A1AA and Coram Healthcare, go to

http://www.alpha1advocacy.org/a1aa_phonocard_program.htm

Testing of Gene Therapy Continues

Applied Genetic Technologies Corporation, AGTC, a privately held clinical stage biotechnology company developing novel human therapeutics, announced that the Company has closed on an \$11,800,000 financing round led by InterWest Partners of Menlo Park, CA. Other participants in the round include Intersouth Partners and MedImmune Ventures, Inc. The investment funds will be used by AGTC to complete the next phase in human clinical trials for its gene therapy treatments for Alpha-1 Antitrypsin Deficiency (Alpha-1) a form of emphysema. Previous human trials have shown the product to be well tolerated and can provide sustained expression of the therapeutic protein. The next planned clinical study will determine if therapeutic levels of alpha-1 antitrypsin can be achieved by increasing the dose of AGTC's Alpha-1 product administered to patients.

COPD Foundation Announced Launch of Lung Health Check on WebMD

The COPD Foundation announces launch of the Lung Health Check, developed in an educational collaboration with WebMD. Development of the Lung Health Check was made possible by funding from the COPD Foundation.

The Lung Health Check is an educational platform at <http://www.webmd.com/lung-disease-health-check/default.htm> that both teaches the key symptoms and risks of developing lung disease, and suggests appropriate steps to take to prevent or manage disease. This solution offers a quick check on the effects that a breathing problem is having on a person's life, and offers suggestions both for those already diagnosed with a lung problem and those with respiratory symptoms as yet undiagnosed. The Lung Health Check will not give out medical advice, but is intended to serve as an educational resource and tool.

"The COPD Foundation is extremely excited about this collaboration with WebMD and to be able to provide a resource on lung health," said John W. Walsh, President of the COPD Foundation. Walsh said the new platform will help "inform, educate, empower and engage individuals to learn more about their lung health," and enable more effective interaction with healthcare providers. "Those of us already diagnosed with lung conditions like COPD understand the importance of early and complete diagnosis and the value of 'learn more breathe better'," said Walsh. He also said that the Lung Health Check will be "a resource to millions of people searching for answers" to their shortness of breath.

"Millions have been diagnosed with lung problems and millions more have symptoms suggesting a possible lung

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Coram is a national provider of multiple augmentation therapies for alpha-1 antitrypsin deficiency patients. Our alpha-1 program includes:

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problem, shortness of breath or cough or phlegm production, but remain undiagnosed,” said Byron Thomashow, MD, Chairman of the COPD Foundation. “Most lung problems are treatable but can only be treated if properly diagnosed,” Thomashow said. “The Lung Health Check allows people with respiratory complaints to get a better idea of their lung health and then share the results with their healthcare provider. For some, the Lung Health Check may be a place to start. For others it may be a place to gauge one’s progress.”

After completing the Lung Health Check, users receive three customized reports that focus on various aspects of health and offer suggestions such as how to ask for help, reduce stress, get better sleep and stay active. This online solution is designed to assist both health care providers—physicians, nurses, respiratory therapists—and people concerned about their own lung health or that of their family members. Patients can print the reports and bring them to a physician, which may aid in diagnosis.

The Lung Health Check also provides access to a wealth of information and resources. It teaches people to take an active role in managing their disease, including how to follow a medication regimen, and explains the kinds of testing needed for proper diagnosis (such as spirometry for COPD).

The Lung Health Check is just one of several programs the COPD Foundation has created to spread awareness of COPD for the year 2010, which the World Health Organization has designated “The Year of the Lung.” The Lung Health Check is an educational collaboration between WebMD and the COPD Foundation. The Lung Health Check is not a program of the American Thoracic Society.

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iGive.com is an Internet organization that allows you to designate your favorite charity as the beneficiary of your online shopping. The Alpha-1 Advocacy Alliance is one such charity that benefits. Over seven

hundred (700+) member stores donate a percentage, ranging from 1% to 26%, of what you spend with them. This can add up to sizable donations for our group. You probably already shop at some of the stores, such as Lands’ End, JCPenney, Office Depot, Amazon, and Staples.

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ARALAST [Alpha-1-Proteinase Inhibitor (Human)] is indicated for chronic augmentation therapy in patients having congenital deficiency of A₁-PI with clinically evident emphysema. ARALAST is not indicated as therapy for lung disease patients in whom congenital A₁-PI deficiency has not been established.

Important Safety Information

- ARALAST is contraindicated in individuals with selective IgA deficiencies (IgA level less than 15mg/dL) who have known antibody against IgA, since they may experience severe reactions, including a severe, potentially life-threatening allergic reaction to IgA, which may be present.
- ARALAST is made from human plasma. It may carry a risk of transmitting infectious agents, e.g. viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent.
- The most common symptoms during the clinical study were headache (0.3%) and sleepiness (0.3%). Post market adverse event data have indicated reports of infusion site pain associated with the administration of ARALAST.

Reference: 1. ARALAST (Alpha-1-proteinase inhibitor (human)) Prescribing Information. Baxter Healthcare Corporation, 2006. Baxter, ARALAST and ARALAST AATmosphere are trademarks of Baxter International Inc. May 2008 HYL3662

GINA Took Effect on May 21, 2009

from the Alpha1Health.com Newsroom

May 21, 2009 was an important date for Alphas. This was the day that Title I (relating to health insurance) of the Genetic Information Nondiscrimination Act (GINA) takes effect. What does this mean for you? It means that, effective May 21, 2009, health insurers and health plan administrators are prohibited from requesting or requiring genetic information from you or from your family members. It also means that genetic information can not be used for making decisions about insurance coverage, rates or preexisting conditions. The GINA bill is especially significant for Alphas. Since Alpha-1 is a genetic condition, testing family members for Alpha-1 is important. With GINA, Alphas can now feel reassured that family members who may test positive will be protected.

In November, GINA (Title II) will take effect. This means Alphas will be further protected from discrimination by employers in terms of hiring, firing or promotion decisions. Learn more about GINA from the National Human Genome Research Institute.

Deciding about Transplant: One Person's Story

by Nancy Ryan

I am Nancy Ryan. I am 66, turning 67 in September. At the present time, I am looking into a transplant evaluation. This has been a very long road for me and I will explain.

When I was 33, I started having difficulty breathing. I was in the middle of a divorce and the doctors said it was asthma and I had no reason then not to believe this (it was around 1975). I did Aerobics and Jazzercise, but could not do it well; I just thought I was out of shape. Eight years later, in 1983 when I was 41, both my parents died four months apart—my mom of colon-liver cancer and my dad from emphysema, enlarged heart, failing kidneys, heart attack, and so on. I continued to be told that I suffered from asthma brought on by emotions which still made sense to me. Seven years later, at the age of 48, I had bronchitis which I could not seem to get rid of and finally was diagnosed correctly; I am an Alpha-1 ZZ.

My primary care doctor sent me to a pulmonary doctor who informed me I was at 25–26% breathability and needed to be evaluated for a transplant immediately. I chose to go to the University of Pittsburgh for an evaluation. There I was told my lungs were really terrible, but because I was very functional they wanted me to come back every six months for the pulmonary doctor to watch my progression and decide when I should be listed. Finally, after all this time, I was very comfortable with this decision. So many thoughts, so many things were happening in my life and I was quite apprehensive about all of this, but was always told by my doctors at home if I didn't have one I would surely die soon.

I returned there every six months but, before even a year was over, my insurance changed at work and I could no longer see my pulmonary doctor, nor could I go to Pittsburgh anymore. In 1991 I had a major colon surgery where they removed most of my colon. While recovering from that surgery, I was advised by my doctors to take disability from work. I was awarded long-term disability and remained on disability until I was rolled over into retirement last year and had to go on Medicare.

In 1993 when I was 51 and under the care of a new pulmonary doctor, I was put on oxygen. I was sick all the time and he recommended I be evaluated once again. With my new Insurance, I had to go to the University of Minnesota and I was put on the list but told I was still quite functional. By this time, I was leery of transplants as I had learned so much more and a lot of tragedies were going on around me so I went inactive on the list and have never had one yet to this day.

All these years I have had many major surgeries, including kidney cancer which kept me off of any list for at least five years to make sure I was cancer free. My kidney was removed in March 1999 and I am so fortunate to be cancer free now for 10 years. All these years I have chosen NOT to have a transplant, but decided instead to live healthy, eat healthy, take good vitamin supplements and use many medications, including Prolastin infusions (which I have been on since 1991). I

also have been in a pulmonary rehabilitation program since 1990 as I personally feel that exercise is more important than most anything we can do for ourselves. I am doing pretty well except for my lungs. At my last PFT my FEV1 was 0.45 and my DLCO showed that my lungs are three-quarters full of air, which I cannot get out. All this time, I have had many different doctors due to insurance changes.

All these years, I have been told I need a transplant, but I have been dragging my feet and I have been in denial even to myself. Now, however, I can no longer remain in self-denial which I feel I have been able to do very well. In reality I have seen myself decline to where I no longer have much real quality in my life. I recently volunteered to do three six-minute walk tests for a study regarding different types of portable oxygen usage. The first one I did I was stopped at three minutes because my sats dropped so low, then rested and made it to six minutes but my sats had fallen to 87%. Any activity seems to make my sats start dropping. I really do push myself very hard to do things, but my sats now fall pretty quickly, so I only do what I have to do.

I have been very fortunate to reach this far, but I can't really say it has been easy. Each year I deny that I am getting worse, but in reality I know I am. The cutoff age for a transplant used to be 60, then it went to 65 and now at many transplant hospitals the age is 70 and greater depending on a person's overall health. I am in pulmonary rehab and have been for years. Things are so different now than what they were when I first sought a transplant. They know so much more, many things have improved and many hospitals believe Alpha-1 patients should have a double lung transplant and I agree.

By sharing my experiences, I hope I have answered many questions about deciding on transplantation. I am still somewhat apprehensive of having a transplant, but I am confident that now it is time. I can go to the grocery store, but cannot carry my groceries in the house, my son does that for me. Doing laundry is a nightmare because going down the basement steps is easy, but coming up is like climbing a mountain that keeps getting higher every time I climb them. I cannot go shopping anymore because I cannot walk far and end up feeling helpless. So many things I wish I could do; even taking a shower is a major chore.

By waiting I have seen the birth of my two granddaughters, which I never dreamed I would and I have seen my adult children grow into fine adults and parents themselves. I also had a wonderful furry friend for 10 years until last year when she developed mast cell cancer and had to be put down. I still think about her all the time and really hope someday I can get another one, when I know that I can really care for it.

I have been blessed to have a very determined mind and have been able to do as well as I have for so long. If I do qualify for a transplant, I am really hoping, as we all do, for it to be a successful one, but I also know it can go the other way and I am very aware of this also.



Alpha-1 Advocacy Alliance
PO Box 202
Wolftown, VA 22748

FOR INFO CALL: 540-948-6777
Toll Free: 1-866-FOR-A1AA
Fax #: 540-948-6763
<http://www.alpha1advocacy.org>

Inside: Ann Marie Benzinger Had Her Double-lung Transplant

THE ALPHA-1 FAMILY PROVIDING INFORMATION AND EDUCATION TO THE COMMUNITY.

Dealing Post Transplant with Skin Cancers: Part 2

Since my last article kicked off my dealings cancer post transplant, I've enjoyed the feedback. I had hoped things would be better this go around as I cover what I've been doing since October of last year.

I had MIs, Pet Scans and follow up dermatology doctor visits. The results proved that I'd have to go to the next level. Moh's surgeries did work at first, plus the freezing just were not getting the job done so once again had to move on to something new. That's where I begin this article on dealing with post transplant cancers.

I was referred to the head of the head and neck & throat otolaryngology. I was feeling optimistic this guy would guide me through stuff and I could get back to living a little more without the doctor visits. I was set up with a "few" additional docs, but first they have more blood draws, more Pet Scans and MRIs. Please ensure your covered with any potential kidney issues before the tests. All these meds we must take post transplant do terrible things to us, especially the dyes and such they put in the testing process. I can't take any chances anymore so it's discussed not just between the doctors, but also myself each time I get loaded into the system. Remember throughout your days and nights after your transplant—the old way is out, have to adjust to what is going to happen or be aware of warning signs. Having a good trusting "Team" is a must.

In November, I was set up with my radiation doctors and a plan was set up to receive daily radiation treatments as well as with the chemo doctors who would have me receiving chemo every Tuesday. They all (radiation, chemo, pulmonary,

dermatology, etc.) in turn had discussions about case. I started and at first didn't feel too bad. Next thing I knew I was receiving blood infusions as my iron was messed up. The New Year has seen some changes that really threw me for a loop. My left cheek had a swelling which looked to me like Pinocchio's nose and it was big.

More MRI and Pet Scan to look into this strange happening. More cancer found, so back into it with a "stronger" dose of the chemo rounds. Finally, about early March, it appeared Pinocchio was gone from the building. That month wasn't a favorite of mine to say the least. I waited 60 years but had my first accident (totaled my truck) due to my blood sugar dropping. I was the only one hurt, but with everything else happening, it was something.

Other issues started taking a toll with my body. My fears have come to my worst thoughts. Yes the facial nerves are held tightly by the cancer as it's wrapped around it and prevents any facial or eye brow movements or eyes dry out. I've had to use nighttime eye drops of a gel to keep my eyes moist and during the day it's some other drops. My fear (and that of the doctors) is this may be a lifetime condition. However, having lived with and dealt with Alpha-1, I know I'm very blessed to still be quickly closing in on my 10th year from my transplant, and 23 years of Alpha-1. For now I'll close and return in the future to further share my journey post transplant. My youngest daughter gave me a button that closely expresses things: "I've Survived Nearly Everything!" Catch you up next newsletter. Stay well, healthy and smile. It's less tiring.
