# Bruno Bytes - March, 2015

## On the topic of the D68 Enterovirus Causing Paralysis 3/31/2015

Dr. Bruno's Post: The Mutated D68 Virus Likely Caused Paralysis.

I know this finding is no surprise. Enteroviruses cause paralysis. And viruses mutate. Remember that it was recently discovered that Type 1 polio virus mutated in the Congo causing a 40% death rate and paralysis and young adults instead of infants.

So the D68 virus mutating is no shocker nor is it something to be terrified of. D68 is not "THE NEW POLIO!" There were 107 cases of weakness or paralysis compared to thousands of children with just the respiratory illness for hospitalized and what the CDC estimates are millions of children who were infected and basically got just a cold.

These numbers are a lot better than those for the polio epidemics. Anti-bodies were drawn before and after the huge 1948 North Carolina polio epidemic where 70% of children were infected with the poliovirus, about 5% developed "non-paralytic polio" and 1% to 2% were paralyzed. If you apply those numbers to the D68 outbreak, there should have been at least 10,000 cases of paralysis or weakness last year, not 107... Link found between children with paralysis and 'more polio-like' strain of enterovirus D68, study says.

http://www.washingtonpost.com/news/to-your-health/wp/2015/03/30/link-found-between-children-with-paralysis-and-polio-like-strain-of-enterovirus-d68-study-says/

## On the topic of Having a Blood Test to Determine Antibodies for the Polio Virus 3/30/2015

Dr. Bruno's Post - Anyone can have a blood test to see if they have antibodies to the poliovirus. Anyone who had polio or the vaccines would have poliovirus antibodies. If you saw the 60 Minutes piece <a href="http://www.cbsnews.com/news/polio-cancer-treatment-duke-university-60-minutes-scott-pelley/">http://www.cbsnews.com/news/polio-cancer-treatment-duke-university-60-minutes-scott-pelley/</a> you may have noticed that a graphic showed a poliovirus receptor on the cancer cell grabbing the virus. What's more, a researcher said that the modified, non-paralytic poliovirus, once inside the brain tumor cells, damages the cells (just as it did to your normal neurons), opens them up and thereby makes cancer cells "visible" and able to be attacked by the immune system. This is interesting because poliovirus receptors are 1) only found in less than 8% of humans (polio survivors' being in that lucky 8%); 2) receptors are found on normal human small intestine, lung, liver, heart cells, even though the poliovirus does NOT damage those cells; 3) functioning poliovirus receptors apparently are found on liver, kidney and lung cancer cells.

This is fortunate for using poliovirus as a treatment but raises the question as to why cancer cells express functioning poliovirus receptors? Is it possible, when this study has treated more than a couple of dozen patients (half of whom have died), that it will turn out that only 8% of people with cancer will have their cancerous cells infected and damaged by the injection of poliovirus? Let's hope not! (They are bypassing the blood, where the antibodies are, by injecting directly into the tumor, which is "hidden" from the immune system until the poliovirus breaks it apart).

## On the topic of Building Stamina 3/29/2015

Question: I'm looking for ways to build my stamina, is it possible? Any suggestions? Dr. Bruno's Response: Try the Post-Polio Diet, Protein Power: Eat Well, Be Well http://www.postpolioinfo.com/library/prodiet.pdf

## On the topic of Bowel and Swallowing Issues 3/28/2015

Question: Dr. Bruno, I keep on trying to block out anything to do with the Polio . . . as I truly think this is not healthy. That being said, if I had any medical training, I'd look into the neuro-pathways of the very few times that I felt the throat muscles give out when I was taking a sip of water; causing me to really choke. In addition, I'd research the very few instances that for about 2 to 3 days, my bowels just seem to get into a 'funk' and decide not to push what they should (like in a rhythmic sequence); but yet I'll be in cramps with nothing moving until I gather up the courage to buy over the counter, what I seem to need.

As a kid, I remember something called Neocultol that at times my Mom had to give me (it was a chocolate flavored, thick gelatin like laxative). But, it's only recently that I've been having these excruciatingly painful episodes.

I'm uncomfortable bringing up issues like this at our Support Group. Deep down, I know it has something to do with the Polio. Can you help me with this?

Dr. Bruno's Response: I think I get the gist of your question. It sounds like you are asking about blocking your thinking about anything polio related and also asking about occasional constipation.

The polio belly and dealing with constipation article is in the Post-Polio Library - http://postpolioinfo.com/library/SlowGuts.pdf

With regard to blocking out thinking about past polio experiences or current symptoms that may be related to polio, I agree that that's not the best thing that one can do for their mental or physical health. This is where a good psychotherapist comes in handy so that you can discuss the underlying fear of just "thinking" about polio. I hope this helps.

## On the topic of Polio Survivors and PTSD 3/26/2015

Question: For some unknown reason, I just had a flashback to when I had polio. I had a mild case and it wasn't until afterwards that the doctors realized it was polio.

I had had surgery on both feet to correct some serious problems (that were not related to polio). While I was confined to bed (during the recovery), and the only way I could get around was crawling or someone helping me transfer to a wheelchair. In the night, while I was lying in bed, I became fearful what would happen if the house caught fire; and I could not get out. I started panicking. I can't have been the only survivor who has had that feeling. When I started teaching, I was always aware of how to get my students out, and no matter where I am, I am always checking to see 'how to get out'. It isn't a major disruption in my activities, but I am becoming more aware again of being in places where, if I am on crutches, I could take a fall, or not be able to get through...(like when people put chairs in the aisles and block exits).

I came "unglued" last week when our church set up chairs, and there was only one aisle for everyone to use. I was on crutches, my friend was in a wheelchair (both legs amputated), and another person was on a walker. My PTSD was not from this, but from being raped in college, and then having my first husband seriously abused me in front of our children. About 5 years ago, I had a major flashback and husband quickly got me to our doctor. I wonder how many of us *do* have flashbacks that go back to when we were incapacitated and felt trapped (especially those of us who were older).

Dr. Bruno's Response: In our experience Polio survivors who were disabled early in life (especially if they were hospitalized and neglected by staff) are nearly universally afraid of fire and being trapped. Many of our patients have very powerful memories of abuse and terror after being thrown into the pool for "physical therapy," and being trapped in their beds when they had an urgent need.

Fortunately, very few of our patients have flashbacks and, and perhaps surprisingly, we have never had a patient who even came close to meeting the criteria for PTSD. I think the reason for that is, (Continued)

order to set the stage for PTSD later in life, one has to understand the concept of death, which most children do not

Children in the hospital were terrorized and terrified. If someone had polio later in life they were much more able to advocate for themselves and to understand that the lack of care and even the abuse that they experienced was not going to lead to their dying, so the conditions were not there to set the stage for PTSD.

Additional Question: Based on what you said about older children advocating for themselves. "What happens with grown individuals who are in the military and experience flashbacks?"

Dr. Bruno's Response: I mentioned that older polio survivors were more able to advocate for themselves and realized that, in spite of abandonment and abuse, they were not going to die. What happened with grown individuals who are in the military and experience flashbacks? Service members in combat and had people shooting at them and trying to blow them up, clear and present dangers that could very well kill them or they saw kill fellow service members. It's the fear of death and seeing others die that sets the stage or PTSD. Death is the key factor.

## On the topic of Electrolyte Panels 3/26/2015

Question: This part of an article from emedicine.com. I wonder whether this type of test is part of a normal blood workup at a general, annual physical? Is this something we should ask for? I have quoted from article:

"An electrolyte panel is a blood test that measures the levels of electrolytes and carbon dioxide in your blood. Electrolytes are minerals, such as sodium and potassium that are found in the body. They keep your body's fluids in balance and help keep your body working normally, including your heart rhythm, muscle contraction, and brain function.

Carbon dioxide (CO2) is also measured in this test. CO2 is a waste product made when the body breaks down food for energy (metabolism). It takes the form of bicarbonate in the blood, so this part of the test is sometimes called a bicarbonate test. Bicarbonate helps your blood stay at the right pH.

Your doctor may order an electrolyte panel as part of a regular health examination. Your doctor may use this test to check on or diagnose a medical condition. Your doctor can also use an electrolyte panel to see if any medicines that you take have changed your electrolyte levels.

An electrolyte panel measures the blood levels of sodium, potassium, chloride, and carbon dioxide. For more information, see the topics:

- Sodium.
- Potassium.
- •Chloride.
- Carbon Dioxide (Bicarbonate)"

Dr. Bruno's Response: High venous carbon dioxide or bicarbonate can suggest you're not exhaling strongly enough to blow off carbon dioxide. We always write for, in addition to CBC for anemia and electrolytes, TSH and T4 to check thyroid function and CK to see if muscles are breaking down. Before starting a statin, a CK baseline is vital.

## On the topic of PPS actually being Post Polio Sequelae 3/25/2015

Question: This quote is from an article from México Post- Polio Litaff Applac http://postpolioproblemadediscapacidad.blogspot.com/2010/07/accept-existence-post-poliosyndrome.html?spref=fb#sthash.uFHDCTjT.dpuf

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"This satisfaction is even greater because this year, the World Health Organization (WHO) finally included this syndrome in Clasificación Internacional de Enfermedades within the G14 code corresponding to the central nervous system diseases. WHO (World Health Organization) states that PPS is, "an evolution of an irreversible and incurable clinical situation in relation to the progressive dysfunction of the motor units, which cannot be classified as sequelae of polio". Question for you: How can it NOT be Sequelae of Polio?

Dr. Bruno's Response: The "doctor" who wrote the new G14 code, replacing the ICD-9 138 code, is not an expert on polio or PPS. I complained to the WHO about the draft definition which, by the way, says that only muscle weakness is a sequelae of polio and is the ONLY symptom required for a PPS diagnosis. Of course, I had no response from WHO. So the "new" definition is not only a return to the ignorance of 1985 but also just plain wrong.

Questioner's Response: "And we wonder why we can't get good, consistent care?"

## On the topic of Intravenous Immunoglobulin (IVIG) treating PPS 3/23/15

Dr. Bruno's Post: I've been writing since 2004 about the failure of intravenous immunoglobulin (IVIG) as a treatment for PPS in spite of glowing "press releases" from the IVIG manufacturers (please see below). Independent researchers have reviewed the published studies on IVIG in 508 polio survivors and have just come to the same conclusion:

# Intravenous Immunoglobulin for Post Polio Syndrome: A Systematic Review and Meta-Analysis

Yao-Hsien Huang, et al. BMC Neurology 2015, Number: 39 March 22, 2015

#### **Summary**

Background: Post-Polio syndrome (PPS) is characterized by progressive disabilities that develop decades after prior paralytic poliomyelitis. Because chronic inflammation has been suggested as causing the development of PPS, immunomodulatory management, such as intravenous immunoglobulin (IVIg) administration, may be beneficial.

Methods: We performed a systematic review and combined analysis of 3 published randomized, placebo-controlled trials of 241 patients and 5 prospective studies of 267 patients that evaluated the effect of IVIg in managing PPS. Pain severity, fatigue, muscle strength, physical performance and, quality of life were measured before and after IVIg infusion.

Conclusion: The present review indicated that IVIg is unlikely to produce significant improvements in pain, fatigue, or muscle strength. Thus, routinely administering IVIg to patients with PPS is not recommended.

(Article Posted Next Page)



#### INTRAVENOUS IMMUNOGLOBULIN (IVIG) DOES NOT TREAT PPS

Dr. Richard L. Bruno, Chairperson International Post-Polio Task Force and Director International Centre for Polio Education
<a href="https://www.PostPolioInfo.com">www.PostPolioInfo.com</a>

Let me tell you an unbelievable story, and I mean literally unbelievable.

Sweden, 2004 – "Xepol" was described in the Karolinska Institute press release headlined "Promising anti-inflammatory treatment for post-polio syndrome." Sixteen polio survivors with muscle weakness were treated with Xepol, which is intravenous immunoglobulin (IVIG), a standard treatment for inflammatory diseases. "Most patients reported improvements in their physical status. However, the value of this is unclear, since this first study did not include a placebo group." Value unclear without a placebo group? No kidding.

Sweden, 2006- A Xepol study was finally published in a medical journal. IVIG was given to 73 polio survivors and placebo to 69, then given again in three months. There was no improvement in fatigue, general muscle strength, pain, walking speed, balance or sleep quality. There were only four benefits: A "selected study muscle" increased in strength by 2%, a greater decrease in "significant pain," a 10% increase in reported "vitality" and a 19% increase in physical activity compared to the placebo group.

Did Xepol help polio survivors? First, the placebo group had worse symptoms than the Xepol group to begin with, making it harder for them to show any benefit. Second, this was not a placebo-controlled study. IVIG subjects had noticeable and unpleasant side-effects as compared to the placebo group: 30% reported itching and rash with IV, 29% reported headache, 19% reported nausea and 10% reported feeling cold. Since as many as 30% of the Xepol subjects could have figured out that they were getting IVIG, any improvements could be due to the placebo effect.

Sweden, 2008 - A press release trumpeted, "PHARMALINK REPORTS POSITIVE RESULTS FOR XEPOL," "effective and well tolerated" in the same subjects reported in the 2006 journal article, but who were now one year post treatment. Pain, walking ability and self-report of health "all showed significant and clinically meaningful results," the release hailed. Said Pharmalink's managing director, "We are very excited about this data as patients in the treated group have experienced a reduction in disease symptoms after just 12 months."

Whoa! First, the published six-month study showed no significant improvement in pain or walking ability. Second, since the new twelve-month data hasn't been published, so we can't know if any of the new results produce a "significant and clinically meaningful reduction in disease symptoms." Third, even the release said that the placebo group also reported a decrease in pain and improved walking after 12 months.

Finally, the company was "very excited" because polio survivors had a reduction in symptoms "just 12 months" after taking Xepol?" "Just 12 months?" Can you imagine any drug company excitedly proclaiming, "NEW HEADACHE MEDICATION WORKS JUST 12 MONTHS AFTER TAKING THE PILL?"

North America, 2009 – I received e-mails from polio survivors in the US and Mexico. Doctors were making presentations about Xepol to post-polio support groups and then asking polio survivors for donations to perform studies using Xepol.

Sweden, 2010 – "Pharmalink AB, today announced agreement with Grifols for the acquisition of Xepol (R)...human immunoglobulin for the treatment of (PPS). This agreement marks a significant milestone in Pharmalink's corporate development. Grifols will develop the PPS product opportunity. In several clinical trials lead by a team of physicians at Karolinska Institutet, immunoglobulin has shown significant and clinically

meaningful results in pain, walking ability and quality of life by down-regulating the inflammatory process in the nervous system of PPS patients."

"Significant and clinically meaningful results in pain, walking ability and quality of life?" Not in the one published study. And, none of the studies, published or not, ever measured "down-regulating the inflammatory process."

What is "significant" is the "milestone in Pharmalink's corporate development," having sold Xepol to a company with the cash to "develop the PPS product opportunity" without polio survivors having to fund it. I've been around long enough to remember a 1995 NIH study that found that high doses of prednisone, the king of anti-inflammatory drugs, didn't decrease PPS symptoms but did cause horrible side effects. A 2007 Norwegian study found no change in polio survivors' "fatigue and muscle strength" three months after IVIG treatment."

One post-polio boat sailed long ago: Inflammation does not cause PPS. That is unless you're a corporation that "publishes" research via "very excited" press releases and happens to have a "product opportunity" that may make you a buck... or 1,500 bucks, the cost of just one Xepol treatment.

## On the topic of Blood Pressure Medications 3/19/2015

Question: My doctor put me on 2.5 mg Lisinopril - the lowest dose (an ACE) for my blood pressure. No problems, it just didn't drop my BP, so this month he upped it to 10 mg. After about 4 days I had the worse deep dry cough ever, so messaged him... of course was Friday so I heard nothing. The cough was continuous and harsh so I stopped the Lisinopril on my own. I finally reached him, and today he called in a script for 50 mg of Losartan (an ARB), but this drug also shows a side effect of "dry cough" so am concerned (as I'm still getting over the horrendous coughing from the Lisinopril. Anyone here have experience with either of these meds? Dr. Bruno do you have any advice on this?

Dr. Bruno's Response: Please see my article: Cardiac Drugs, High Blood Pressure and Polio Survivors http://www.postpolioinfo.com/library/CardiacDrugs.pdf

## On the topic of Calcium Supplements 3/17/2015

Dr. Bruno's Post: Do Polio Survivors Have to Choose Between Their Hearts and Their Bones?

"Hold the Calcium Supplements" NY Times March 16, 2015 By C. Claiborne Ray

Q. I have been told that women should stop taking calcium supplements after menopause, as there is a danger of heart attack and stroke. Is this true?

A. "Several large, credible studies have reported a higher incidence of heart attacks in both men and women who take calcium supplements," said Dr. Orli R. Etingin, (Director of the Iris Cantor Women's Health Center at NewYork-Presbyterian Hospital/Weill Cornell Medical Center).

The total intake associated with these adverse outcomes was 1,200 milligrams a day, she said.

The mechanism by which calcium could promote heart attacks is entirely unclear, Dr. Etingin said. The studies were all done in men and women in their mid-50s and older, who are at highest risk for cardiovascular events, and it is not clear if the results apply to younger groups. Nevertheless, she said, many doctors are now recommending dropping calcium as a supplement at all ages, replacing it with dietary calcium.

Many patients ask if calcium is actually deposited in blood vessels, causing calcified atherosclerotic plaque, "but that does not seem to be the case, based on these and other studies," Dr. Etingin said. (continued)

She added that she usually recommended, as a replacement guide, three or four portions of calcium-rich foods each day. Each serving of a dairy product, like cheese, yogurt or milk, contains about 300 to 400 milligrams of calcium, and many other foods, like orange juice, may have added calcium. Some green vegetables contain it as well.

For patients worried about bone density, she said, it could be monitored at intervals to verify its stability on the new regime.

## On the topic of Fatigue 3/16/2015

Question: I am tired all the time but sometimes I forget just how bad it gets. I swear I could sleep away the rest of my life! The doctor ordered 2 pages worth of blood tests but my follow-up appointment isn't for 3 weeks yet. I am so anxious to see if they find anything other than PPS that is causing this! They have already ruled out thyroid & all the 'normal' things like vitamin deficiencies. Feeling tired.

Dr. Bruno's Response: First of all, a sleep study is vital for all polio survivors with fatigue. They need to put wires on your muscles, legs and arms. 50% of polio survivors have muscle twitching that disturbs sleep and half of them don't even know it! We found that

Alprazolam 30' before bed is what we have found stops twitching. DON'T let a doc give you Requip or Mirapex or any drug that affects dopamine. Polio survivors should NEVER mess with brain dopamine.

That being said, if you have Parkinson's you usually start with non-dopamine replacing medications and then work your way up because the dopamine receptors become less sensitive when they're stimulated by drugs like Mirapex, the can drug stop working or cause abnormal movements (as in Michael J Fox).

\*If you need an MAOI that naturally increases brain dopamine, then you need it and should take it.

We did a study of a drug called bromocriptine, to treat Parkinson's in polio survivors who did not respond to "conserve to preserve" and found it was helpful. However, the side effects are unpleasant and these were a handful of patients out of hundreds who did not respond to self-care "treatments." Here is the article in http://www.postpolioinfo.com/library/DRUG.pdf about bromocriptine in treating post-polio fatigue. I don't recommend taking it.

## On the topic of Sir Arthur Clarke 3/15/15

Dr. Bruno's Post: Arthur C. Clarke: "LORD BUDDHA?"

I had once considered compiling and publishing my e-mails and calls with Arthur. I've even thought of using them to write a piece for the stage, "Arthur's Outing." And, although he was a public figure and not truly my patient, he was a friend and I can't reveal his confidences. All that needs t be known about this post-polio patient is in this wonderful article.

Arthur as "Lord Buddha?" I bow to that.

http://www.thedailybeast.com/articles/2015/03/14/inside-arthur-c-clarke-s-mysterious-world.html

### On the topic of The Internment of Polio Survivor Cardinal Edward Egan 3/10/15

Dr. Bruno's Post: On the occasion of his interment, the International Centre for Polio Education and International Post-Polio Task Force give thanks for the generosity and compassion of New York polio survivor Edward Cardinal Egen. His eminence Edward Cardinal Egen asked that the following message be included in at least two of the Parish Bulletins published during the month of April.

Message From the Cardinal: Polio – Not Gone, But Forgotten.

(Continued)

"April marks the anniversary of the polio vaccine. Today, as many as 57% of Americans are not adequately vaccinated against all childhood diseases, including polio. At the same time, 1 million American polio survivors are reporting Post-Polio Sequelae (PPS), disabling mid-life fatigue, weakness and pain. Yet, too few doctors and polio survivors know that the symptoms of PPS exist and are treatable.

As a polio survivor, I personally know the consequences of this terrible disease and urgently encourage vaccination against it and for polio survivors to receive treatment for PPS.

For more information about polio and PPS please go to www.PostPolioInfo.com."

## On a NIH Study of Polio Survivors and Corticosteroids 3/6/15

Question: I remember some years ago NIH wanted to inject polio survivors with corticosteroids to see what would happen. I asked my physiatrist, (also chief of rehab medicine for the VA) about it. He said I could go but if I did, never come to see him again. The point is: we deal with the after effects of polio, but we are not subject to the notion of "Let's see what this will do."

Dr. Bruno's Response: "The NIH in fact did a study giving oral corticosteroids to Polio survivors based on the assumption that there was inflammation in the spinal cord. Not only where the steroids unsuccessful in treating weakness, fatigue but they in fact caused weakness and fatigue as well as depression. It took me the better part of the year to clean up the mess they made of polio survivors lives."

## On the topic of Medical Deductions for People with Disabilities 3/5/15

Dr. Bruno's Post – "The IRS regulation states "any device that mitigates the effect of the disability can be listed as a medical deduction." This would include solar panels, a hot tub or electric can opener, all without the necessity of a prescription."

## On the topic of Spinal Cord Stimulator Therapy 3/5/15

Question: My doctor wants to put in the trial "spinal cord stimulator therapy" and if it helps with my chronic pain (back, hips, and leg pain) then he wants to put in the permanent one. I appreciate any info and discussion.

Dr. Bruno's Response: "I can't even count the number of polio survivors who have had stimulators implanted and have been in more pain than without.... And then had to have the stimulator electrodes removed! Polio survivors hate electrical stimulation, even the use of tens units. Someone needs to find the reason you have pain and treat it and not electrocute it away."

http://www.webmd.com/pain-management/news/20100510/electrical-stimulation-may-ease-back-pain?page=2

# On the topic of "pressure pain" and being "sway backed" 3/2/15

Question: Does anyone else have pressure pain from sitting or lying under their tailbone? Mine isn't the tailbone itself but the skin and tissue below. I am very swaybacked and as a result my tailbone protrudes. With loss of muscle and padding around the area I feel like the area is being stretched. I don't see any visible breakdown of the skin but it really hurts. I have tried the coccyx cushion but that hasn't helped either because it mostly feels like it's the tissue and skin being stretched and split from the inside out. Clothing, such as the seam in any pants including pajama pants only irritates it worse. Wheelchairs and skirts don't mix well. I went to a new doc last month about my hip pain that is constant but worse when I'm in bed. After X-rays and a CT scan the doc said he couldn't do anything for my hip but could give me a cortisone injection in the coccyx so maybe I could sleep on my back. I guess he felt like he had to offer something. I scheduled it but the more I thought about it, the more hesitant I became and cancelled it at the last minute. (Continued)

Cortisone would only further breakdown of the integrity of the skin and tissue there and probably cause additional problems down the road. Again, it isn't a bone injury that is causing it. I am in my wheelchair or bed 99% of the time. I'm so frustrated trying to get proper medical attention and being met with shrugs at every turn. Has anyone else had this problem and found a solution? What kind of doctor can properly treat this too?

Dr. Bruno's Response: "There are a few possibilities that come to mind. First is for you to lower the foot rests on your wheelchair which will drop your legs and make you less swaybacked. Another option is to put a wedge beneath your wheelchair cushion, again to drop your legs in front and raise your pelvis to make you less swaybacked.

Finally, a simple solution is a reverse "U shaped" cushion, like cushions that are placed on toilet seats that have the open portion in the back instead of in the front. That would put the weight on your pelvis instead of your coccyx. In addition, there are wheelchair cushions that have compartments were you can add or remove foam to leave the area near your coccyx open. Have you tried any of these?

## On the topic of the Side Effects of Beta Blockers 3/2/15

Question: I have been taking a beta blocker for blood pressure. I was curious as to the side effects, so I stopped taking it. I slept well, and actually woke up in a good mood. I did not experience, what was always a problem of shortness of breath, until late in the evening. As I read the side effects to my wife, she confirmed many of them. Interesting for sure.

Dr. Bruno's Response: Please read my article - Cardiac Drugs, High Blood Pressure and Polio Survivors http://www.postpolioinfo.com/library/CardiacDrugs.pdf