Gary Schoener
4033 Dupont ^ve. South
^innea^olis, MN 55409

11/22/89

Dear Gary,

I picked u p the mail as I was driven home from ^ohns Hopkins this noon and was distressed to learn of the probelms you have with that beautiful boy. Let us hope that they work out. Along with your other serious probelms.

There is hope. Remember, I had my first thrombosis in 1975 and I've had a number since then and the Georgetown surgeons did not expect me to survive their early-morning emergency surgery in 1981. There is hope a d you both continue to hope.

I'll be writing a brief account of my immediate medical future separately when I have more use of the right arm. They did the catheterization through that forearm abd it is still stiff and sore and I'm to make only light use of it for a while. I do need a bypass, without a vein they can use. They'll use the mammory arteries which they say we can spare.

Although I could anticipate what you report about Ed Williams I also hoped that when he said he did want help but didn't trust those he saw that he might trust you.

Less pointedly I've been telling him what you say you did. He kept saying he was listening and would but obviously he didn't. I heard from him often after he phoned you but not, I'm happy to day, for several weeks.

Please excuse me for not correcting the typos.

Lil has been having a bad siege of some undiagnosed throat and chest rtoubel along with what ha off and onn for years caused her to lose her voice. For a month now. Took her back to the family doctor last week after she'd been on an antibiotic for a week and he put her on another one and made appointments for an ENT man to see her and for chest X-rays. They're this coming ^onday and we see him Tuesday, when he'll have their reports and will remove my stitches.

I've no phohibition against driving so I'm taking her out to supper in a fe minutes.

We are going to friends for Thanksgiving tomorrow and it is fortunate that I phoned othe friends to see how they were making out because the man told me that his wife was making thanksgiving dinner for us and would bring it, although she has been limping for months. Hungarian refugee girl whose life was saved during World War II by a local black man. They married and have been friends for several decades. She wa in school on the other side of the river, Buda or ^est, when the US first attacked t at city. Blew the bridges and she'd not had a word about her family since. The Hungarian government and ours were not helpful when - tried to get some word.

Chip Selby, who did that great documentary Reasonable ^oubt as his master's thesis, brought me home from ^opkins. As he did after my cataract operation. Fine young man.

Our hopes are with you!

Best,

Harold

Gary Richard Schoener
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19 November 1989

Dear Harold,

Sorry to hear about your continuing medical problems. I hope that things do get sorted out. We've had friends struggling with the same issues.

As for Ed Williams, he did phone and we finally connected, and I did agree to write you. After lengthy discussions, of which I'm sure you already can guess the content, he continued with endless conspiracy theories. Any attempt to discuss one simply led him to change the topic, and I had to yell at him to get his attention. What I ended up doing was this:

1. agreeing that his theories, no matter how improbable, could be true...that I had no way to challenge them;

2. Noting that I, like you, had every right to have our own beliefs and theories...and that he had the right to his;

3. But, that he did not have the right to insist that we either believe or listen to his theories and charges...

   a. that he had no more likelihood of convincing either of us than we apparently did of convincing him

   b. that such arguments were distasteful

   c. that his constant insistence, pressure, and verbal press was incredibly annoying

In conclusion, I told him that I wasn't in a position to decide whether he was sane or not, and in any event if he denied that he needed help there was little I could do about it and a referral would make no difference. However, if he expects to be on any sort of reasonable terms with Harold Weisberg or anyone else on the planet he'd better:

1. respect their boundaries and views

2. cut out the harrassing arguments

I noted that it would be better for him to discuss things other than the case, conspiracies, etc. That true friends don't harrass each other.

I too felt sad. He's a decent fellow, but impossible to deal with. Furthermore, he's got little interest in getting help and would be impossible to work with. What a waste!

As for our family, we've been struggling with a number of things. On the positive side, the bindery at long last has our monster of a book--all 852 pages of it (8 1/2 X 11" format)! We've gotten a good price of $ 8.75/copy for library binding with the best materials and with oversewing. (once we got to commercial printing we can do Smythe sewing).

My wife Katherine, who's Director of Marketing for a large HMO, has had her job get worse and worse. She's been working 80 hour weeks and been taking a lot of grief from some of the new young vice presidents. Now they are going to cut her staff, so the work will only get worse. So, she ended up in a confrontation and now is either leaving or being forced out or both. So, we're trying to negociate some type of reasonable severance. Without her income we can't make it very long.. (We've refinanced our house and within several years could make it on one income...but weren't ready yet for this.)

This Spring, out of the blue, an endocrinologist raised a question as to whether Alex had a Prader-Willi syndrome. We had gone in to see him because Alex has bi-lateral undescended testicles. Since he's a bit porky, the doctors couldn't feel them, so they needed to test if they were there. The endocrinologist injects a hormone to stimulate them, and if then there is measureable testosterone output, you can be sure they're there.

Well, suddenly Prader-Willi was suggested: it has three symptoms. Poor muscle tone of unknown origin, lack of control of eating, undescended testicles. At age 1 year Alex had gained a lot of weight, and that's what brought it up. Well, after genetic testing and other things, we learned that you really can't tell for sure until he's age 4,5, or 6. He's not got the genetic sign, but neither do half of the kids who have it. So, we've got to wait and see. If he has it the outcome will be grim--expectations are for a bad disposition, constant hunger, and the need to put him in a group home where the kitchen can be locked up. He will end up with a low IQ--possibly around 70! So, it's a parent's nightmare--especially parents in their 40's where the child is destined to outlive you by many years. So, keep your fingers crossed. That's all that we can do.

The waiting is terrible, but we've refocused our energies on day to day things. He's now walking, although since he weighs 40 lbs. he's a bit wobbly. He wears clothes of a 5 year old and outweighs some 4 year olds. He's stilla wonderful, smiley little boy who's a real joy. We've switched from physical therapy to evaluations for speech & language therapies. The PT thinks he'll make it on his own, but he's behind intellectually. Fortunately, the school system here has great services, so we're also pretty much switching from hospital-based services to those offered by the schools.

Maybe 4 years from now we'll look back and sigh a sigh of relief. I sure hope so. For now it's a nail-biter.

On another topic, with our book out I'm hoping to have some more chances to get out and speak or give expert testimony, so I expect I'll have a chance to visit you and Lil sometime in the year ahead. I've made it on some TV interview shows and may well be on others...as I've told people--we don't have an advertising/marketing budget for the book--I'm it!

Give my best to Lil.