From: Andrea Sloan
Date: Friday, August 23, 2013 8:41 AM
To: Jean-Jacques Bienaimé , Henry Fuchs
Cc: "Levenback, Charles F"
Subject: Thank you for considering Andrea Sloan's Request

Dear Mr. Bienaime and Dr. Fuchs,

My name is Andrea Sloan. I am 45 years old and I am living an amazing life that happens to include living with ovarian cancer. By now, I imagine that you have heard of me and heard a little about my story. I just wanted to reach out personally to you both to thank you for considering my very personal request to be given access to BMN 673. I feel compelled to put a face to this request so I have included several photos—all of which (with the exception of 1) have been taken within the last couple of months. Several of them were taken within the last two weeks. I hope you can tell from them that I have an AMAZING life and that I am healthy and have lots more life to live! I can only imagine how many of these requests you get, none more deserving than the next. Having said that, I can only make this plea on my behalf. So, with extreme appreciation, I thank you for considering my request.

If there is anything at all that I can provide to aid in your decision-making, please do not hesitate to let me know. I know that my doctor, Charles Levenback, is attempting to contact both of you now via email to explain why my treating physicians all think that BMN 673 is THE WAY TO GO for me! While there are certainly no guarantees about how my body would respond to this drug, we are all optimistic that this drug CAN significantly extend my life. Thank you for considering giving me the opportunity to try it.

With gratitude,

Andrea
[redacted]

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From: Henry Fuchs
Sent: Friday, August 23, 2013 1:42 PM
To: Andrea Sloan; Jean-Jacques Bienaime
Cc: Levenback,Charles F
Subject: Re: Thank you for considering Andrea Sloan's Request

Dear Ms. Sloan,

First accept my heartfelt concern that you find yourself in this position. I've learned only a little bit about you, but know that you have given a great deal of yourself to those less fortunate and in great need.

And likewise, it's for patients like you and others who have a substantial zest for life that inspire us at BioMarin. Whether we're in business leadership positions like JJ Bienaime (our CEO) or in medical scientific positions like myself as Chief Medical Officer, it's our privilege to work on behalf of those who can and those who can't advocate for themselves.

When patients have exhausted all options for approved therapy, we believe it's in patients individual and collective best interest to participate in clinical trials where we test formally whether optimism and hope can be fulfilled. While BMN673 looks promising, we do not know yet whether it works, and in whom it works. We need to go through the clinical trials process because we want patients to have access to therapies if they are scientifically proven to work.

We're happy to speak with Dr. Levenback about our ongoing trials, so that he has the most current information about ongoing and planned trials and can provide you with the best possible choices. I see that he has e mailed me and will arrange to speak to him as soon as I can.

In the meantime, please know that we are indeed giving you and people like you due and fair consideration.

Best regards,
Henry J. Fuchs, MD
Chief Medical Officer,
BioMarin Pharmaceutical, Inc.

From: Andrea Sloan
Sent: Friday, August 23, 2013 7:29 PM
To: Henry Fuchs
Cc: Charles F Levenback
Subject: Re: Thank you for considering Andrea Sloan's Request

Dear Dr. Fuchs,

Let me say again how much I appreciate your responsiveness to both me and Dr. Levenback today.

I have spoken with him since receipt of this email. He conveyed to me his appreciation of your willingness to discuss my particular case with him. I certainly don't want to speak for him, but I believe that Dr. Levenback left the conversation with a greater appreciation of the company's position with respect to making this drug available to me. Having said that, he did convey to me his continued opinion that I am an excellent candidate for this drug and his belief that I would be an excellent responder. It is unfortunate that nothing is ever as black and white as we would like it to be...although when you need a drug that can quite possibly extend your life, the lines start becoming a bit more clear.

I believe so strongly in the potential of BMN 673 to significantly extend my life that I simply cannot stop trying to convince you to take a chance and give it to me. I understand the decision is not simple or made in a vacuum, but I did want to reconvey that Dr. Levenback and I continue to believe that, if available to me, this drug would be an excellent option.

Best wishes for a happy weekend. I look forward to continued dialogue on this important issue.

Andrea

From: Andrea Sloan
Date: Friday, August 23, 2013 2:31 PM
To: Hanry Fuchs, Jean-Jacques Bienaimé
Cc: "Levenback,Charles F", "Vince Haley", "Kyle Janek",
Subject: Re: Thank you for considering Andrea Sloan's Request

Dear Dr. Fuchs,

I apologize for yet another interruption, but I am writing to request a point of clarification. From the very earliest correspondence with your company, I have been informed that there are no clinical trials for BMN 673 currently recruiting for ovarian cancer. However, I am receiving email after email from friends who have made contact with your company in which the company has told my friends that clinical trial options should be explored between the company and my doctor. I certainly hope this is not intentional, but it does tend to confuse the recipients who are receiving this information into thinking there are clinical trial avenues that I might explore when, in fact, it is my understanding that there are not. Any light you can shed would be most appreciated. In the event that there is not an OPEN and AVAILABLE trial that I would qualify for using BMN 673, I think it would, again, save everyone lots of "tail chasing" time not to allude to the presence of something that doesn't exist. Of course, I may misunderstand and would appreciate any clarification you can give me.

Best,
Andrea

On Aug 23, 2013, at 2:34 PM, "Andrea Sloan" wrote:

Dear Dr. Fuchs,

Thank you for the courtesy of your very timely reply. I appreciate it greatly. I know that your time is valuable and that this takes you away from your regular work of changing the world for thousands of people.

Just so I am clear about what I am asking and so that I understand what I am being told exactly: Is the company willing to discuss granting me use of this medication under an "expanded use" exception with Dr. Levenback, or are you telling me that you will be happy to speak with him about clinical trials? I am sure you can understand that given my diagnoses, I cannot wait for future clinical trials. I have been told by your company that there are no open ovarian cancer trials currently. Hence, the specific request for "expanded use." I just want to make sure that any communication between the parties is productive for all involved and focused on the real issue – which is that there are no clinical trials and that I need an expanded use exception.

I know I sound like a broken record at this point, but it is because I know—and my doctors believe—that your PARP inhibitor is my best shot at a long and productive life. I 100% understand that there are no guarantees and that my tumor might have no response at all to your drug. Having said that, I am confident in saying that the team of doctors that are working side-by-side with me (and have been for the last 7 years) are excited about the prospect of what this drug could do for me. All I am asking is for a chance. In speaking with the FDA, it is my understanding that there have not been safety issues with this drug. The drug is currently sitting on a shelf a few floors away from where I am getting treatment. The FDA has communicated that I am an EXCELLENT candidate for expanded use. My doctors know how to administer this drug. I would love for my doctors to be able to tell you how rock-star my tumor is when it comes to responding. Would you agree to leave the door open for further discussion about the appropriateness of compassionate/expanded use? As dramatic as it sounds to say it, my wonderful life really does depend on it.

I have copied former Speaker Newt Gingrich and Texas Health and Human Services Executive Commissioner Dr. Kyle Janek on this correspondence as I understand that both have been awaiting replies to their inquiries on this matter.

All my best,

Andrea

CC: Speaker Newt Gingrich
Executive Commissioner Dr. Kyle Janek

On Aug 23, 2013, at 6:30 PM, "Henry Fuchs" wrote:

Hi Andrea,

We are not currently recruiting patients with ovarian cancer to clinical trials. We are evaluating whether to conduct additional clinical trials in ovarian cancer but have not come to a conclusion yet. And I can't give you a time frame in which a conclusion might be reached.

Similarly, we have not initiated expanded use trials of the drug. We are evaluating whether and when to conduct such trials, but have not come to a conclusion yet, and no time frame has been set for reaching such a conclusion.

I have been in touch with Dr. Levenback and we both agree that he is in the best position to explore your options with you. I've introduced Dr. Levenback to Dr. Gallant in my group who can provide further assistance in my absence.

All the best,

Hank

From: Jean-Jacques Bienaime
Date: September 8, 2013, 5:31:06 PM CDT
To:
Cc: Henry Fuchs, Ed Von Pervieux, Eric Davis, Philip Lo Scalzo, Debra Charlesworth, Rich Ranieri
Subject: Re: The time is now to grant Single Patient Access to Andrea Sloan

Hank,
As you said it is time to refocus the message on competitive PARP's available. Although is the assertion that there are no trials of PARP inhibitors currently enrolling in ovarian cancer correct?
Debra,
Have you engaged the PR agency?
JJ

Sent from my iPhone

On Sep 8, 2013, at 2:36 PM, wrote:

Mr. Bienaime,

It has been 6 weeks since doctors at MD Anderson told Andrea Sloan that her BRCA1 Ovarian Cancer is back. Again. For the fifth time. It has been 6 weeks since they said to her, "There are NO clinical trials of PARP inhibitors currently enrolling ovarian cancer patients. The best possible treatment option is the most-promising (top of class) PARP inhibitor BMN 673. We can petition FDA for Single Patient Access if the manufacturer, BioMarin, agrees to provide the drug."

It has been a month since FDA said, in short "Andrea you are a great candidate; we have no safety concerns for you trying this drug given its data to date, your history and your prognosis. Get the manufacturer to agree to provide the drug, and we'll move on your doctors' application within 2-3 days."

Yet BioMarin has unilaterally held up Andrea's treatment with misinformation & disconnected responses. The inept corporate messaging or misguided early responses can be forgiven -- must be forgiven -- but the company must admit its prior error and fix this, today. While BioMarin hems and haws over the FDA-approved Single Patient Access for Andrea, her inoperable cancer bomb ticks. It's time, BioMarin. Put on your superhero capes and JUST SAY YES.

30,000 people are not "mistaken," http://t.co/Ci9kIOHqK4 They see the simple truth, which is that there is no excuse for sentencing Andrea Sloan to certain death just because BioMarin has egg on its face for several weeks of pointless delay.

Single Patient Access does not "open a floodgate," because it requires case by case consideration, and the number of patients innprecisely Andrea's situation at this

time is miniscule. Single Patient Access for one trapped in a recurrance between clinical trials does not make recruiting for future trials difficult: by definition, Single Patient Access is available only to patients to whom no clinical trial is currently available. Once you have a trial open to OC patients, they will not be eligible to apply for compassionate use. Don't martyr Andrea just because cancer visited her after phase 1 & 2 trials closed but before phase 3 launched.

BioMarin's stated mission is to provide hope & treatment to patients with unmet serious medical needs. That's what drove me to place my order with my broker for BioMarin stock.

If, as is widely speculated, you are delaying Andrea's approval fir "business" reasons such as merger or acquisition discussions, BioMarin will pay a steep price in the court of public opinion. Likewise, if investors are enjoying the benefits of a rapidly rising share price fueled in part by Andrea's inadvertent advertising of just how promising your new drug is, shame on them. Such business interests should be wholly divorced from and have no influence whatever on the scientific, medical and moral standards that should drive decisions on Single Patient Access. I am a small shareholder, but one with high expectations that you, sir, and this company will live up to the promise to be the company that offers hope to patients with serious unmet needs.

This is life or death for Andrea Sloan. She has demonstrated compassion and sacrifice and selflessness throughout her life, including when she supported me through my breast cancer battle 17 years ago and every day for the past decade through her work on behalf of indigent women and children who are victims of domestic violence and abuse. You must help her, with all deliberate speed. JUST SAY YES! RIGHT NOW!

(sent from my iPhone)

Sent from Yahoo! Mail for iPad

From: Debra Charlesworth
Date: September 8, 2013, 6:57:56 PM CDT
To: Jean-Jacques Bienaime
Cc: Henry Fuchs, Ed Von Pervieux, Eric Davis, Philip Lo Scalzo, Rich Ranieri
Subject: Re: The time is now to grant Single Patient Access to Andrea Sloan

Should have SOW on Mon.

Debra Charlesworth
Director, Corporate Communications

BioMarin Pharmaceutical Inc.
105 Digital Dr.
Novato, CA 94949

Tel [redacted]
Mob [redacted]
[redacted]
www.BMRN.com

From: Michelle Wittenburg
Sent: Monday, September 09, 2013 7:46 AM
To: Jean-Jacques Bienaime, Henry Fuchs, Ed Von Pervieux, Eric Davis, Philip Lo Scalzo, Rich Ranieri, Debra Charlesworth
Subject: RE: The time is now to grant Single Patient Access to Andrea Sloan

Good morning. My name is Michelle Wittenburg, and I'm Andrea Sloan's best friend and am contacting you this morning in hopes that I can facilitate a quick resolution to her request for compassionate use of BMN 673. I am in receipt of your email last evening, Mr. Bienaime, copied to your executive team but also to the person who sent you the email, and Ms. Charlesworth, I also received your subsequent reply to that email that you will have a PR company engaged by today. Even in a light most favorable to you, that series of emails reflects a strategy of damage control – the classic dodge and weave, an attempt to displace responsibility and blame on others, and frankly, a CYA; NOTHING IN THOSE EMAILS is reflective of a good faith attempt to be "patient-centric" and to deliver what you have marketed as a very promising drug to Andrea Sloan, through a clinicial trial setting (to answer the question you posed, Mr. Bienaime, you are correct that there are no trials of PARP inhibitors currently enrolling ovarian cancer patients for which Andrea would qualify – despite BioMarin's offers over the past several weeks to help Andrea's world class physicians "find" such a trial for her) or compassionate use. I have been in daily contact with a multitude of senators and congressmen, and they are a pretty fair bunch. While they have advocated strongly for Andrea's interest because they see the clear moral imperative in place in this situation and do not buy that a single grant of compassionate use to an objectively qualified candidate will destroy the clinical trial setting from now until eternity, they have been steady about advising me to keep an open and fair mind as to BioMarin and to your motives and to give you the chance to perform your due diligence in hopes of the outcome that we know Andrea needs, and until now, I have kept that open mind. I think these same elected officials will be profoundly disappointed in the text and tone of your emails from last evening – NO ONE likes being duped or played, especially congressmen, I have found.

I have not, at this time, shared your email beyond a close circle of advisors, and it is not my intent, at this particular time, to share it beyond that circle; that said, since you are engaging a PR firm (you will definitely need one

after your emails of last evening) to help you wage your war against a cancer victim, you have certainly provided me with a new tool for my arsenal. I would much rather have Dr. Levenback receive a phone call AND email from you by the close of business today (5 pm, CST) that you have reconsidered the course of action you are intending to take and that instead, you have found new enlightenment in regard to compassionate use as to Andrea Sloan. Perhaps one avenue to communicate this very concrete sentiment and plan is on a conference call that Congressman Culberson is attempting to arrange with you and Dr. Levenback and others. You may reach Dr. Levenback at [redacted] and [redacted].

Regardless, I will call Dr. Levenback upon my arrival in Washington, D.C. later today, and I hope that we have found a peaceable resolution to something that has played out for too long and certainly at the expense of one person – Andrea Sloan. She, too, is eager for resolution, and is ready to publicly thank you for showing that you CAN BE the patient-centric company that you claim to be.

Michelle Wittenburg
Governmental Affairs Consultant & Attorney at Law
[redacted] office [redacted] cell [redacted] fax
[redacted]

---------- Forwarded message ----------
From: Date: Fri, Sep 20, 2013 at 5:01 PM
Subject: RESPONSE RE: ANDREA SLOAN
To: JEAN-JACQUES BIENAIME

The response I received has nothing to do with what I asked.
Once again, why are you denying Andrea Sloan BMN673 under compassionate use?
She meets all criteria.
Please respond.
Thank you,
Dear Ms. ,

Thank you for your unsolicited inquiry regarding compassionate use of BMN 673 [a poly ADP-ribose polymerase (PARP) inhibitor] which is currently in clinical development for genetically defined cancers. BMN 673 has investigational status in the US; it is not approved in any countries globally, including the US.

We have the utmost concern and respect for human life. BioMarin has firsthand experience working with patients with rare diseases, many of which are life threatening or fatal, and acknowledges the frustration that many feel due to a lack of treatment options.

As a company, we do support preapproval expanded access programs. We implement these programs when we have sufficient scientific evidence to support both the safety and the efficacy of a product for an indication. Additionally, we implement these programs only when we can ensure that access will be provided equitably, ensuring that the process is appropriately blinded, and when we are confident that the expanded access will not inhibit our clinical trial plans or clinical trials for a disease generally.

The more quickly we can move an experimental therapy through the clinical trial process, the sooner we will know if the therapy is safe and works. A scientifically proven and approved therapy will help the most patients. That is why we are focused on conducting rigorous clinical trials to ensure that a product has an appropriate risk benefit profile. We are working towards the greatest good for the greatest number of patients.

Although the current data from BMN 673 that we have looks promising, there is no data at this point to support anything beyond dosing and some preliminary safety. It is too early to know if the experimental therapy is safe or effective, or will even prolong life, until we conduct the appropriate Phase 3 trials. The data that we have is from an ongoing early stage clinical trial, and it is the first trial that we have ever done with this therapy in humans. Therefore, we believe that it is premature to implement an expanded access program for BMN 673 at this very early stage in the product's development.

We are aware of four other compounds in development for BRCA mutation ovarian cancer, including Rucaparib, Veliparib, Niraparib and Olaparib. Information regarding current clinical trials for these compounds, including recruitment status and eligibility criteria, can be found at http://clinicaltrials.gov

Note, a recent search on http://clinicaltrials.gov for clinical trials involving PARP inhibitors for the treatment of ovarian cancer retrieved approximately 15 trials in various stages of recruitment.

Current information on BioMarin's clinical program for BMN 673 is available at http://www.biomarinclinicaltrials.com and http://clinicaltrials.gov

Thank you for your interest in our company's research efforts. If you have additional questions or if you received this information and did not specifically request this information, please contact the BioMarin Medical Information Services by phone (800) 983-4587 or (651) 523-0310, fax (866) 524-0038 or email medinfo@bmrn.com.

Sincerely,
Lucy S. Hodge, PharmD, PhD
Medical Information
On behalf of BioMarin Pharmaceutical Inc.
Case [redacted]
Tel [redacted]
medinfo@bmrn.com

Mr. Bienaime,

Andrea does not ask that you make the drug prematurely available to women who are earlier in the course of the disease. This is a wholly different situation. Her options are to obtain your PARP inhibitor by compassionate use or to remain untreated and face certain death in a matter of months. Please take the time to read the FDA guidance and the Roche whitepaper somthat you understand the difference. You could do so in 30 minutes time.

The FDA guidance is here:
http://www.fda.gov/Drugs/DevelopmentApprovaiProcess/HowDrugsareDevelopedandApproved/ApprovalApplications/lnvestigationalNewDrugINDApplication/ucm107434.htm

The Roche position paper is here:
http://www.roche.com/position_on_pre_approval_aocess_on_investigational_medicinal_products.pdf

From: Jean-Jacques Bienaime
Sent: Sunday, September 22, 201310:41 AM
To: [redacted]
Subject: For your own education

Please read below. You claim to be highly educated and intelligent. So hopefully you can understand what you read.

Would you have clamored for insurance companies to pay for Bone Marrow Transplant in breast cancer women in the 1990's before there was any clear evidence of clinical benefits in well controlled clinical trials? Based on your current e-mail regarding Andrea Sloan I would venture to say yes.

You would have been part of a group responsible for the premature deaths of thousands of women.

A sorry illustration of the risks associated with politics and lobbying taking precedent over science.

Ignorance kills.

Please inform yourself before insulting people you do not know about topics you know nothing about.

---------- Forwarded message ----------
From: **Jean-Jacques Bienaime**
Date: Sun, Sep 22, 2013 at 8:02 AM
Subject: Fwd: I DO NOT SUPPORT ANDREA SLOAN
To: [redacted]

FYI.
Regards,

From: Sasha Freddy
Sent: Wednesday, September 18, 2013 7:41 AM
To: Corporate Communications
Subject: I DO NOT SUPPORT ANDREA SLOAN

I seem to be in the minority, but I do NOT support Andrea Sloan, and I wanted to email your company with my thoughts. First of all, let me tell you that I too have stage 3 ovarian cancer. So why have I not jumped on the Andrea Sloan bandwagon?

I would like to share with you what I posted on the Inspire ovarian cancer board. I posted my thoughts last night, Sept 17. I woke up today to find that I cannot log onto Inspire, meaning I have been banned. My post was removed also.
http://www.inspire.com/groups/ovarian-cancer-national-alliance/

Here is what I posted, and it outlines my thoughts on the matter:

I'm sure we are all well aware of the issue of Andrea Sloan trying to get BioMarin to give her the drug BMN 673 based on compassionate use. At first it looked like a simple "cancer patient vs mean drug company" issue, pretty black and white.

The main reason I will not sign the petition is that I don't know enough about her case. There are few details in the press. When she has been asked for details about her medical situation online, such as on her FB page, she deletes the questions and then blocks the person from her page. But before being blocked, there are usually some very hostile comments towards the person asking the questions. As an attorney, I am sure Andrea has to carefully weigh all sides of an issue. I feel the same about this case. I need more information. But she appears to be unwilling to answer any questions about her situation that might be helpful.

Is she in a recurrence now? How extensive is the recurrence? What is the current ca 125? Is she in treatment of any kind now?

What chemo drugs has she been on in the past, and have they gotten her into a remission? How many recurrences/remissions has she had, and what has gotten her into those remissions? What other drugs/treatment plans have been explored? Has Avastin been tried, that is usually well tolerated. What is the basis of her doctor saying 'her body cannot tolerate any more traditional treatments'? What exactly does

that mean, in medical terms? How does he know if her body can withstand the PARP drugs? Has she applied to be in other PARP trials? If the PARP trials are closed, can she apply for 'compassionate use' to get into one?

I have a question about her doctor. Why did he tell her this drug is 'her last hope'? (that is what the articles are stating) The drug is still in phase one trials. BioMarin admits it shows promise, but they really don't have enough data to ensure efficacy. If I recall, I read that only 28 women with ovca were in the phase one clinical trial. How can the doctor proclaim that this drug is her 'last hope', no one can really know that. The drug holds 'promise', yes, but may not be her 'last hope'. What exactly does he mean in medical terms?

Andrea claims to be advocating for everyone, but I just don't see that. What I see is her advocating for herself to get this drug ahead of everyone else who may need it too. I don't feel inclined to single her out and help her get this drug, when there are hundreds upon hundreds of women on this board alone who may need it too. (I'd love to try it too!) There are many on this board alone who are in a similar situation medically as she is, in yet another recurrence and perhaps running out of options.

I feel that Biomarin should continue testing the drug BMN 673, and continue going through the proper channels to get it out onto the market. The drug company cannot just 'willy-nilly' give someone a drug because she is demanding it. It is not properly tested. Her doctor does not know if it is her 'last hope', as even BioMarin is not 100% sure of this drug, that is why it is in clinical trials, to find out.

I intend to email the CEO of BioMarin and tell him I support the company testing the drugs, and making it available to EVERYONE who needs it when clinical trials have proven the drug to be safe and effective.

This is merely my opinion, and it might be quite contrary to how others feel about it. I would appreciate my opinion being respected, as much as I would respect anyone else's opinion on the matter.

(end of post)

You also might be interested to know that I have posted similar questions on 'Andi's Army' page on Facebook. I was greeted by sheer hostility, then my posts there were deleted and I was banned.
It seems Andrea is not willing to answer ANY questions about her medical condition. She does not want anyone delving into her situation, or questioning her in any way, shape or form. She expects everyone to just blindly sign her petition and support her 'cause', without asking ANY questions. It raises huge red flags for me.

Somehow she thinks her life is more valuable than the rest of us with ovarian cancer. I do not want her to get special treatment. Let her stand in line with the rest of us. If and when the drug is properly tested, and if and when it becomes available to EVERYONE who could benefit, then she can have the drug. She comes across in the media as a spoiled, petulant brat!

I hope you will forward this to any pertinent Biomarin executives. I think they will get a kick out of what she is doing behind the scenes..she is all over the internet, trying to 'squash' anyone who DARES to question her.

Sincerely, Sasha

From: [redacted]
Sent: Sunday, September 22, 2013 6:00 PM
To: Jean-Jacques Bienaime
Subject: Frenchmen

Jean-Jacques

Just read the email where you refer to my friend as a "spoiled, petulant brat". You have to be compassionate to have a compassionate use policy. By the way, I would think someone leading a company such as the heartless BioMarin would know how to use email.

Enjoy your weekend Jean-Jackass

----- Forwarded Message -----
From: Jean-Jacques Bienaime
Sent: Sunday, September 22, 2013 8:41 PM
Subject: RE: Frenchmen

I do not know who you are.
I never wrote those words. It was an e-mail from someone else I forwarded.
Please stop communicating with me.
I will ignore future e-mails. I know at BioMarin we are evil people because we are trying to develop life saving therapies.

From: Andrea Sloan
Sent: Sunday, September 22, 2013 4:55 PM
To: Michelle Wittenburg
Cc: Andrea Sloan
Subject: Request for Telephone Call

Dear Jean-Jacques,

I am reaching out to you via email to respectfully request the courtesy of a phone call during which you might directly address my concerns that you are intentionally spreading misinformation to the public, people who are supporting my efforts to gain access to BMN673, and, perhaps most importantly, current and future investors in your company. Should you show me the courtesy of a phone call, this will be the first time since this began that a decision maker has been willing to speak with me.

Until now, I have attempted to allow you to run your internal processes aimed at getting to a solution that we can both live with. I have repeatedly urged my supporters to be respectful of you and the company, and I have been respectful of you in every conversation i have has about BioMarin. I have accepted your company's form letters to me and my family, and have even held my tongue as you have misrepresented the truth to person after person about my doctor's communications with you and also about the availability of clinical trials that you and CMO Hank Fuchs know are not appropriate for me.

I am, therefore, requesting that you personally immediately contact me by no later than 5:00pm CST tomorrow to inform me exactly which of the trials you keep sending to the press and to the public you contend I am eligible for. It is not sufficient for you to hide between "this is a communication for the doctors." You and Dr. Fuchs have engaged in a game of "bait and switch" for over a month. Dr. Fuch's has had Dr. Levenback's phone number for at least that long and both parties have agreed there are no trials for which I am currently eligible. If you contend that there is even one open trial that is recruiting and that given the specifics of my medical condition would enroll me timely, I would like to have that information with specificity.

If you do not immediately communicate directly with me (ie, you and me on a telephone call tomorrow), in addition to going to the national media with your unwillingness to provide this information, I will also make it widely available to every regulatory agency that touches your company. I tell you this not as a threat, but because I have been getting sicker and sicker over the last 5-6 weeks while you disseminate half-truth after half-truth. In fact, as you sat and wrote more emails forwarding information calling me "selfish and self-serving", among other thing, I spent the weekend in the emergency room fighting for my life. I do not intend to let you further defame my medical team or perpetuate lies spun by your PR team at the cost of my life. (Please be aware, as I am sure you are. that it is not your PR firm that owes a fiduciary duty to your shareholders and the investing public--it is YOU and Dr. Fuchs). The dialogue changes tomorrow. I hope that begins with a phone call between you and me. Period.

Please let me know what works with your schedule and the best way to reach you.