

Biopsy of Rhetoric: The Use of Medical Rhetoric in Creating Power Dynamics

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The study of medical rhetoric is essential in constructing a proper understanding in the power of rhetoric. Rhetoric is typically used to gauge how persuasive or influential a text is amongst an audience. Medical rhetoric is crucial because it has the power to persuade an audience much easier than average rhetoric. This is due to the vulnerability of the audience, in most cases the ill, and due to the power placed in the hands of doctors and physicians. Medical rhetoric has the capability to be completely life-altering, largely relying on the presence of the usability scale, which measures how efficient a product or theory is. Many studies looking at the power of medical rhetoric and the various links connected focus on this usability scale. Hannah Bellwoar's study on Meagan, a girl who struggled with fertility issues and those relating to it, looked largely at the way Meagan used outside resources, or those varying from her doctors, to build a perception around her illnesses. The subject essentially found her own forms of research and healing methods through sources she found relevant to her, or from sources she found most appealing. The primary focus of this was to explain and discuss "how everyday literate activity shapes people's understanding of health and medicine," while factoring in this usability scale (Bellwoar 328). While this research is effective and contributes to the discussion of the power of medical rhetoric, as well as many others like it, we rarely see studies focused around the lack of usability, or what happens when information is no longer relevant. We also rarely see a circumstance in which the subject is not able to speak on their behalf of the situation, nor make their own decisions of what was to come. It's also important to note the function of displaced power and the ability of rhetoric to create a new narrative on what constitutes illness and how this creates credibility.

This case study will focus on an 18-month-old girl named Belle, who was misdiagnosed with rhabdomyosarcoma, a rare and aggressive cancer. I will be looking at how the misdiagnosis happened in the first place, looking at the similarities between the cancer and her true diagnosis of a desmoid tumor. I will be looking at her parents, mainly how their reactions differed in severity comparing the initial diagnosis versus the true diagnosis. I will look at the various hospitals that she received treatment at, what their response was to everything and the text they produced on her after. I will look at the medical documents given to Belle's parents, the denied insurance claims, and what lead to these denials. The goal of this case study is to show how medical rhetoric is sterile and credibility is crucial. There's very little room for error and this will show how those errors can remove credibility from a valid illness. This case study will also look at the value of public response and the use of language and imagery as a means of reparation. Most importantly, this case study will look at how power dynamics in the medical field play into medical rhetoric, and how power dynamics are virtually impossible to disregard.

LITERATURE REVIEW

Hannah Bellwoar's case study "Everyday Matters: Reception and Use as Productive Design of Health-Related Texts" focuses primarily on the use of unconventional technologies as a means of creating knowledge through the case study of Meagan. Her goal is to change the perception around how patients receive and learn information regarding their conditions. Bellwoar offers that this study can help patients gain a better understanding of health literacy:

This rethinking of everyday matters of reception offers a different cultural frame, one in which patients' practices are considered as tactical and perceptive rather than passive or noncompliant (1).

This is relevant to my case about Belle, as it offers the framework of creating knowledge. In the case of Meagan, she was capable of making her own decisions and creating informed opinions regarding her condition. Belle's case is in contrast to this notion.

Leslie Seawright's case study "Genre of Power: Police report writers and Readers in the Justice system" focuses on the process of writing police reports and the power that police officers hold in general. The study refers to how police reports are meant to function in a system and how they're given this place of power. She defines the concept of a chained literacy event, in which the report makes its way through the system. This is relevant to my case study about Belle, as it offers a framework for analyzing my own documents and data sent through the health care system that went through its own kind of chained literacy event.

METHODS

In collecting research, I had two methods of gathering data for the case study. My first method was interviewing Pie, Belle's mother. She was able to give a relatively detailed timeline of events in order to get a better understanding of the background of her daughter's story. She provided insight as to how the misdiagnosis happened, the process of getting to the correct diagnosis, her personal mindset and how that shifted accordingly. She provided emails sent back and forth between herself and journalist that were conducting their own interviews with Pie to publish for articles, such as the St. Jude Promise magazine, Niswonger Children's Hospital, and Ballad Health. She sent images from various photo shoots that the hospitals used for postcards, cardboard cutouts, and for the articles. She sent a piece of writing she did when Belle's chemotherapy treatments were done that had every detail of her story and her feelings towards the situation after everything was said and done. The interview is where I gathered my material for niche two of the case study, regarding the power of language and imagery in terms of response and perception.

Pie also provided documents with Belle's treatment plans, consent forms, and denials from their insurance provider. The documents guided me into doing more personal research regarding the power of medical rhetoric. Document analysis was crucial in this case study, as it created my first niche and gave more insight as to how medical rhetoric varies from traditional rhetoric. It gave more information regarding power dynamics and what that means when you switch into a

different field of study. The documents told their own story that I couldn't get out of Pie. They were able to provide concrete evidence and a tangible experience in looking at what Belle's illness and misdiagnosis provided for research into this topic.

Belle's story is unique. Her misdiagnosis was extreme and scary at best. Her family was forced to construct an entire new life for themselves in a week's time. Belle's life depended on the doctors at St. Jude and their confidence in their practice. Her true diagnosis brought a sense of hope to her family and doctors. It provided more insight for other families dealing with this and, in turn, helped the hospital to conduct their own research on Desmoid fibromatosis. Belle was too young to know what was happening to her. None of the decisions made in regards to her health were her choice. It put her family in a situation dominated by vulnerability and blinded trust. Her story allowed for two unique niches to emerge and create a new narrative for what it means for medical rhetoric to hold such immense power and what the factors are that go into that dynamic.

THE CASE - BACKGROUND

Belle Grochowski is a three-year-old girl from Bristol, Tennessee. Her parents, Chip and Pie, are both in the medical field working with the elderly. Chip is a physical therapist and Pie is a speech therapist. They met at a nursing home where they were both working at the time. Chip and Pie welcomed Belle into their lives on July 21st, 2016. The first year and a half of her life was nothing but ease and serenity. When Belle was 18 months old, a mysterious spot appeared on her face. Pie's sister noticed that there was a hard spot on her face, and Pie said that she hadn't noticed it before. In her words, it felt like "a really big pea, right under the skin." Belle's parents took her to the doctor the day after noticing the spot, and the doctor told them that it could possibly be a clogged tear duct. However, they weren't exactly sure what it was, so they referred the family to a hospital to get an ultrasound. The hospital said that it was a complicated cyst, then they were referred to an ENT, where Belle received an antibiotic to take for the next week. Despite taking the antibiotic, the spot got bigger each day. The spot got so large that there was an obstruction in Belle's breathing. Chip and Pie called the ENT again, and they sent Belle to a pseudo-pathologist. They thought that, at the very least, the pathologist could drain whatever was causing the obstruction. However, there was nothing to be drained in or around the nose. The pathologist ended up performing a biopsy and told the family that they needed to get to a cancer institute immediately. On the way home, they called their pediatrician to inform them of the situation. In that 45-minute drive home, St. Jude was calling to set up arrangements to send Belle to Memphis. Upon arriving to St. Jude, the doctors were positive that Belle had a cancer called Rhabdomyosarcoma, a harsh soft tissue cancer that's most prominent in children. Survival rates vary on how aggressive the cancer is, and it seemed as though Belle had a fairly severe case. No one was quite sure if Belle could survive this. For the next week, Belle would undergo surveillance and various tests that would confirm the severity of the cancer. St. Jude had informed Chip and Pie that Belle would have to live in the hospital for 53 weeks, meaning that they would have to completely relocate. In the following week, Belle would have a central line with a chemo port. This would allow for treatments to be easier and faster, considering she would need so many. Pie recalls an interaction with the doctor going over the results of another biopsy. She says that the biopsy was insufficient, which Pie thought was good because it could

be something else. She says that she remembers the doctor looking at her “as if she was trying to tell me ‘don’t be stupid, don’t be naïve’ with her eyes. They were so sure that it was the rhabdo.” One day, while the radiation oncologist was explaining Belle’s step-by-step radiation and chemotherapy treatment, when a different doctor walked in and simply said “hey, it’s not rhabdomyosarcoma.” They gave the option of having surgery, which wasn’t previously available, and created an entirely new treatment for Belle. Her final diagnosis was a desmoid tumor, which was uncommon and a relatively new medical phenomenon.

Pie describes their experience at St. Jude as nice. She mentions that she felt a sense of fear, but also a sense of comfort.

I guess I felt comforted to a certain extent that we were there, you know, cause once they said this is what they think it is, my thought was that we had to get there immediately. I mean, we have to get there and they have to fix this. They were super good. I felt comfort in finally getting there and knowing that they were going to take care of us. I felt like we were at the best place. Like, if we stood a chance at anything, it would be there.

When discussing whether or not she felt any sense of anger or discomfort towards the hospital back home or St. Jude, she said that she couldn’t feel anything in that sense. They thought that her original diagnosis would end up killing her, and this was a far better outcome. In her mind, the worst thing that could happen was some sort of disfigurement.

The worse case scenario was her having some sort of disfigurement, rather than dying. So, I mean, anything was better than what they gave us originally. I hate to say that it was an easy transition, but it kind of was. My mindset wasn’t that she wasn’t going to be with us anymore, but that this was all cosmetic at this point. Or, at least, in comparison. Which is of no significance when you’re thinking about the alternative.

Chip and Pie’s personal research on Belle’s condition came to a halt when the desmoid tumor diagnosis came forward. Since the tumor was so rare and relatively new, there wasn’t enough research on it that differed from what the doctors were telling them. All of their research regarding the rhabdomyosarcoma was essentially tossed out the window.

Once they said it was a desmoid tumor, it threw out everything we thought we knew. Then, they were able to say she’s going to have surgery, this is the chemo she’ll get, and this is how it’ll go down. If it had been the other thing, the occurrence of that is much more than the tumor. And because it’s such a weird thing where it’s not cancer but they treat it like cancer it’s unusual. Once they found out what it was, they sent us home. They sent us home to wait for surgery.

THE CASE – NICHE ONE: POWER DYNAMICS AND MEDICAL RHETORIC

St. Jude created a new treatment plan for Belle that wasn’t drastically different from the treatment plan for rhabdomyosarcoma. It detailed the 53-week treatment, involving chemotherapy sessions, surgery, MRI’s, and general check-ups. Out of the 53-week plan, only

three did not involved some sort of treatment. Since the treatment has ended, Belle regularly goes for checkups at St. Jude to make sure nothing has resurfaced. The treatment plan came with highly detailed lists of side effects, rights to withdraw or to be withdrawn from treatment, privacy and confidentiality rights, etc. The forms also go over what the form means in regards to signing for your child, and how the use of certain nouns- you, I, and we- is in regards to your child.

NON-PROTOCOL INFORMED CONSENT STATEMENT

When we say "you" or "I" in this consent form, we mean you or your child; "we" means the doctors and other staff.

You have cancer. The name given to your cancer is Desmoid fibromatosis. The type and length of treatment will depend on the disease. Your doctor will explain the different treatments that can be used for this cancer. By signing this consent form, you authorize Dr. Sara Helmig and designated assistants to treat you with the detailed treatment plan as shown below. At times you may require care that will be delivered by health care persons who are not employees of St. Jude other than your primary St. Jude physician.

section from the non-protocol informed consent statement regarding Belle's treatment

The non-protocol informed consent statement shown is from the updated consent form that goes into detail about treatment and their rights throughout the treatment process. In the first line, an error is made that describes the desmoid tumor as cancerous. Although the tumor is treated similarly to a cancer, it is not a cancer. The tumor is 100% benign and is easily treatable. Referring to the tumor caused issues with their insurance company removing credibility from Belle's illness and denied her of critical treatments. Multiple claims were made by the insurance that the requests for treatments, such as MRI's, PET, and CT scans, did not meet the "criteria for establishing medical necessity and appropriateness." This was, in large, due to the diagnosis switching from such an extreme to such an alternative. Both treatment plans were sent to their insurance company and they found an obvious fault in the misdiagnosis. The inaccuracies mentioned above also contributed to this. There were too many inconsistencies in written form that caused the insurance company to deny their claims. In addition, St. Jude is completely funded by insurance companies paying for their part of the service and private donations. St. Jude covers all treatment, airfare, food, lodging, etc. for patients and their families. If insurance companies refuse to cover certain aspects of treatment, then it puts the hospital in a tough situation of turning away the patient or paying out of pocket, so to speak.

Denied Service(s) or Supplies

Reference #: **0434589583**
 Place of Service(s): **ST JUDE CHILDRENS RE SEARCH HOSPITAL**
 Service Requested From: **01/03/2018**
 Procedure: **Chest CT**

Based on this review, this service or supply is not approved because it does not satisfy the criteria for establishing medical necessity and appropriateness. As stated in the patient's benefit booklet or subscriber agreement, the patient's program provides benefits for services or supplies only when such services or supplies are determined to be medically necessary and appropriate.

section from insurance claims that were denied

THE CASE – NICHE 2: RESPONSE FROM THE PUBLIC, HOSPITALS, AND THE POWER OF LANGUAGE AND IMAGERY

In the months that followed, several local news sites and the hospitals Belle received treatment at reached out to Chip and Pie for interviews. All of the stories were based on the desmoid tumor and how successful Belle’s recovery has been thus far. None of the stories mention the original diagnosis of the cancer, though. Niswonger Children’s Hospital, the hospital closest to their home, created a postcard about Belle that they sent out to families involved with the hospital and their sponsors. The postcard has a small snippet of an interview with Pie and a photo of Belle after her surgery and treatments had been completed. St. Jude created a cardboard cutout of Belle that sits in a wing of their hospital as well. St. Jude put a spread about Belle and her doctors in one of their monthly issues of their magazine. The objective of this is to help families become more informed of the condition and helps them conduct their own research on the treatment and recovery process. In addition, it gives a sense of hope to those dealing with a similar situation, whether it be the desmoid tumor or a misdiagnosis. Pie thinks that making Belle’s case public and widespread is not only important, but her way of paying the hospital back for what they’ve done for her child. In her words, “there was no way I could have felt anger towards them long-term for all that they’ve done.”



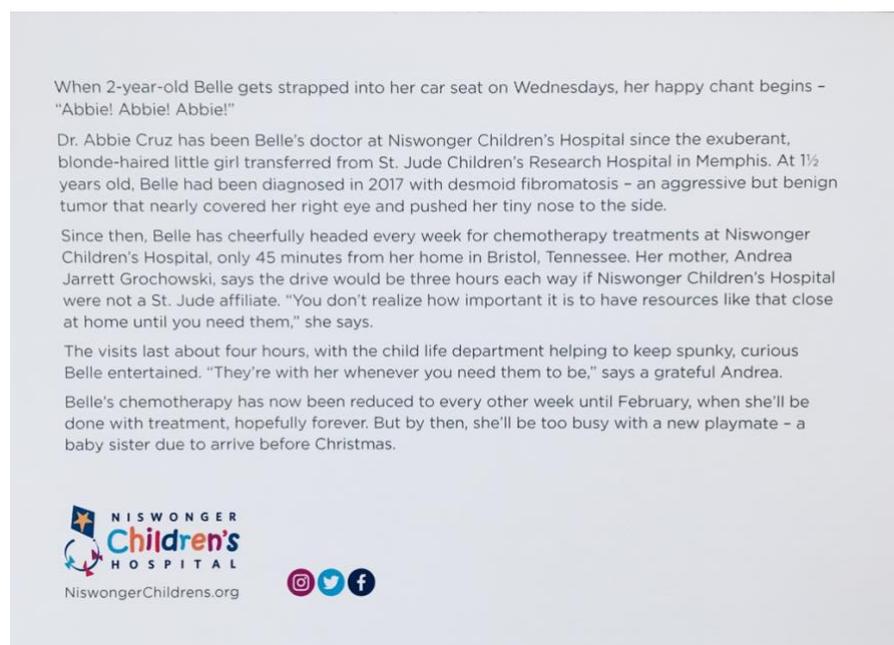
front side of postcard sent out by Niswonger Children’s Hospital, image of Belle on front

The interviews Pie did with these journalists were mostly about her recovery process and the massive success surrounding it. However, none of the articles mention the initial diagnosis of the rhabdomyosarcoma. The main reason surrounding the interviews and publicity is the rarity of

Belle's true diagnosis. There's not a lot of research surrounding desmoid fibromatosis and it shares many of the symptoms of rhabdomyosarcoma. The articles highlight Belle's bubbly personality and discuss her seemingly immediate bounce-back from the surgery to remove the tumor. These are two excerpts from Niswonger Children's Hospital article "The Tiniest Cheerleader," one of the articles regarding Belle's condition:

The massive tumor was removed through her mouth and nose, leaving no scars or disfigurement. "By 4 a.m., she was up and walking the halls, laughing and playing and feeling good," Andrea says with a wave of relief. Within a week, the Grochowskis returned home.

Belle's treatments have extended now to every other week for another six months, then she's done. Hopefully forever. "Honestly, you can't tell anything happened to her," her mother says. "She's just a spunky little thing, nothing holds her down from doing what she wants to do."



back side of postcard sent out by Niswonger Children's Hospital

The articles rely heavily on painting Belle's recovery as a pretty picture, and they're not wrong. Belle had a miraculous recovery with no scarring, no disfigurement, and no complications during the surgery. Her chemotherapy treatments were effective and successful. She lost no hair, she was rarely sick, and suffered from very little side effects. However, the chemotherapy affected her appetite for the time she was receiving treatment and for the following year after. After getting her feeding tube removed, it was a daily struggle to get Belle to eat anything. In a more extreme sense, the chemotherapy has caused Belle to have full body convulsions, similar to seizures. These facts were not mentioned in any of the publications released, largely due to the variable of success and what could have gone wrong during that time. The public response to illness and conditions are critical in the success in treatments and methods of prevention.

ANALYSIS OF FINDINGS

The case study on Belle had two goals. The first goal was to examine medical documents from the hospitals and insurance providers in order to figure out how the misdiagnosis occurred and what power medical rhetoric can hold. This niche was focused around finding a power dynamic present in the medical field and looking at the chain of reactions and decisions made based upon that. The second goal was to look at publications released regarding Belle's condition and gauge how language and imagery elicits a certain public response and concern. Looking at these interviews and images helps to determine if the information the hospitals send out to their patients and donors is useful in creating new knowledge and what kind of emotional response is supposed to emerge from that.

ANALYSIS OF FINDINGS – NICHE ONE

The findings from niche one proved to have the most relevance to the case study. In looking at the insurance claims and the treatment forms, there were clear inconsistencies on the hospitals part that caused their insurance to deny crucial parts of Belle's treatment. The insurance providers hold, in this case, the most power. Since St. Jude is completely funded by insurance companies paying their portion and private donations, they are ultimately subjected to the decision making process of the patient's insurance providers. This puts them at the top of a pyramid of medical power. Following that is the power that doctors and medical professionals hold. Patients typically take what doctors tell them as the predominant truth and expect their explanations about their health to be factual. When a medical professional, or several in Belle's case, fail at this, it's then difficult to gain back the trust of a patient. At the bottom of this pyramid would be the patient. The patient is subjected to the decision making process of treatment from medical professionals and the decision making process of insurance providers. This metaphorical pyramid representing the power dynamic present would be true for Belle's condition. However, the issue with this is that Belle had a unique condition in terms of getting her true diagnosis and in terms of her illness. If we looked at a very standard and moderate case of a patient visiting a doctor, there wouldn't be such a heavy influence of this power dynamic. The only things that would remain true for situations of medical rhetoric would be the doctor having power over the patient in terms of providing information and resources to either construct knowledge about their condition or helping the condition improve. A patient visiting a doctor that has the capability to make decisions for themselves and has the power accept or deny what the doctor is telling them is the variable that makes Belle's case different from others. Belle had no influence, insight, or knowledge in what decisions were made about her health. Everything that was done to her was decided by her parents, the doctors, and her insurance provider. In this pyramid of power, Belle would be placed beneath the patient because of her inability to create her own knowledge and perception on her health. This power dynamic, unique to Belle's case, sparked the chain of events to follow. This involves the misdiagnosis, the true diagnosis, the two different treatment plans, the consent forms, and the insurance denials. If Belle had been capable of making decisions for herself during this process, then there could be a different outcome in terms of her health. We do not see situations like this often that produce such successful results. Belle was lucky in her situation, but still remains subjected to the decision making process of

everyone else. In addition to the findings about power dynamics in the medical field and analyzing what unique power dynamic exists for Belle's case, I was able to create more knowledge about the power that medical rhetoric holds. In the example of Belle's consent form having misinformation of what her condition was, it gave the insurance provider the power to deny treatments for Belle. Additionally, the insurance companies are required to collect all documents from the hospital regarding what their treatments will require. Both sets of treatment plans, the one for rhabdomyosarcoma and desmoid fibromatosis, were sent to the insurance provider. Rhetoric has the power to influence a large audience and change what we thought we knew previously. Medical rhetoric doesn't need to build a case for itself because it's already engrained in our mindset that these professionals are being truthful with us and have the best intentions in regard to our health. We don't consider the other outside elements involved in decisions regarding health. If there hadn't been so many inconsistencies on the hospitals part, the insurance company would have almost definitely approved the coverage of treatments for Belle.

ANALYSIS OF FINDINGS – NICHE TWO

The findings from niche two were less substantial from niche one. In this niche, I looked at the various photos taken of Belle for the hospital to use as promotional ads and articles written about the miraculous success story of her condition. The articles written about Belle were almost cookie cutter and identical in format and story line. None differed in much variety from the others, as they were all written by journalist for the hospital. When looking at the power of language, all of the articles shared the same basis of portraying Belle in a particular light. She's a happy girl that went through a terrible condition and came out the same way she went into it. She suffered no disfigurement, no change in attitude, and will not suffer any long term effects from her treatment. The articles give description of Belle and her family and show how they could go through something so drastic and still come out strong. Language is important in this case because it completely alters the public perception of what the illness is and what the average success could look like. This is helpful to families experiencing a similar situation to Belle because it gives a general feeling of hope. However, this is harmful for creating knowledge for the rest of the public. Not everyone is going to have the exact same treatment, the same recovery, nor the same success as Belle. The texts provided by Pie were conclusive of the fact that Belle survived and will be okay. The hospitals are proud of that, and the family is relieved. Regardless, they don't show quite enough evidence at the actual The photos used for promotion, however, gave more insight into the power of imagery. Photos of Belle after treatment showed a healthy young girl. She had no scarring on her face, no disfigurement, and she had all of her hair. This forces the public to conduct their own personal research of what desmoid fibromatosis really is. Looking at a young girl that recovered from the treatments so seamlessly and having that as a basis of knowledge is potentially harmful as well. If these publications had been completely honest, they would have posted the before images along with the process of removing the tumor. However, the power of medical rhetoric is turbulent. Hospitals want to gain the trust of the average civilian, and they do this by showcasing their best works. This niche was more so a guide in helping develop the first niche, as it showed how medical rhetoric is crucial in gaging the public perception and response to these publications.



Belle the night before surgery to remove the tumor

CONCLUSION

Belle's case is unique in the medical field and in the scope of average life. The case meant to give a look into the power dynamics present that influence medical rhetoric. This was split into two separate niches, the first being a document analysis and the findings leading to a breakdown of the relevant power dynamic present in Belle's situation. The second niche ended up becoming supporting evidence for the power of medical rhetoric and focused on the use of language and imagery to support this.

The study had limitations in terms of hearing the perspectives of more individuals involved in the situation. Belle will never fully understand what happened, and is still too young to really grasp the severity of the situation she was placed in. Speaking to her about her condition would have been impossible. If the doctors were available for interviews regarding their findings and what lead them to the initial diagnosis, it would have provided more insight on that. If the insurance agencies were able to provide their personal reasoning for denying insurance claims for treatment, that would have contributed heavily to the first niche. I was only able to speak to Belle's mother, who was also the one making the majority of the decisions for Belle during the process. It would have been more beneficial to the overall findings of the case to get a perspective that was removed from bias.

More research is crucial in getting a better understanding of medical rhetoric and the power dynamics associated with such situations. Looking at more children that went through something similar, or who are suffering from a sever illness would help to further the situation. Comparing this case to the situation of an adult would provide insight on how power dynamics are fluid and and change according to whether or not the patient is capable of their own decision making process. These assumptions for further research would be valid because of the lack of research

surrounding the fluidity of power dynamics. Focusing on the medical field and how its rhetoric differs from others is important because humanity relies so heavily on the modern day healthcare system.

Belle's case proves that power dynamics in the medical field heavily influence the persuasion of medical rhetoric, language, and imagery that are used to create knowledge.

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PRIMARY SOURCE

Non-protocol informed consent statement that entailed her treatment plan and rights during treatment.

11-18-'19 09:56 FROM- NHC Bristol

2766690384

T-084 P0005/0041 F-948

Patient ID#: 49253

Date: 1/11/18

Patient Name: Belle Grochowski

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NON-PROTOCOL INFORMED CONSENT STATEMENT

When we say "you" or "I" in this consent form, we mean you or your child; "we" means the doctors and other staff.

You have cancer. The name given to your cancer is Desmoid fibromatosis. The type and length of treatment will depend on the disease. Your doctor will explain the different treatments that can be used for this cancer. By signing this consent form, you authorize Dr. Sara Helmig and designated assistants to treat you with the detailed treatment plan as shown below. At times you may require care that will be delivered by health care persons who are not employees of St. Jude other than your primary St. Jude physician.

This consent form gives you information about the treatment, which will be discussed with you. Once you understand the treatment, and if you agree to take part, you will be asked to sign this consent form. You will be given a copy to keep.

Before you learn about the treatment, it is important that you know the following:

- Whether or not you take part in this treatment is entirely up to you.
- If you decide not to have the treatment, or to withdraw from the treatment at any time, you will not lose the benefits of routine medical care.
- You may choose to receive other treatment(s), if available.
- You may choose to transfer your care to another institution at your or your insurance company's expense.