APPENDIX A

Initial experiences with invasive meningococcal disease: Insights from survivors and their caregivers

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Appendix A. Acute phase: Quotes from survivor and caregiver interviews

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Pre-diagnosis phase

Age groups (at diagnosis)	Supporting quotes
Reported by survivors	
Infancy	• *When I got sick, I was **perfectly and totally healthy** the day before I contracted meningitis. I was **a normal, healthy, happy baby**.* • *I was more of like an **energetic type of baby**. That's how I can describe myself most from what I've heard was energetic.*
Childhood	• *It was a **fairly normal childhood**. I grew up in XX, XX a city. I loved going to school and being very active, doing lots of sports and physical activity. Let's see. There were some stressors at home that made home life a little difficult. I don't want to really go into that. Definitely, I was a child and life was a lot more simple back then. I just went to school and played and that was it. After, a lot changed.* • *Yeah, I was the **perfectly average, healthy child**. I was…home videos suggest that I was a little bit more introverted. I wasn't a high energy, like [noises], running around kind of kid.*
Adulthood	• *Sure. So I was…At the time, I was a freshman in college. I had walked onto my school's rowing team, so I was learning how to row a crew and also attending classes every day. And so I was **working out and training** probably 2 to 3 hours a day, attending classes, and then…* • *I was a **regular college student** getting ready to transfer to a 4-year university, so I was finalizing that semester. It was a busy semester and it was a normal day turning in a paper. And it was yeah, just your normal college student just trying to finish up the semester.* • *My **health was great.** I was in college. I was in the **best shape of my life**. I was working out regularly at the school gym. I was going to classes. I worked on the school newspaper, and I had a part-time job working for a weekly newspaper outside of XX.* • *I can, yeah. Up until that point, I was 19 years old. I was 10-feet tall and bulletproof, as teenagers think that they probably are. **Normal lifestyle.** Drove a vehicle, was in college, I was in a fraternity, had normal social, whatever you would consider pretty typical 19-year-old college behavior to be. That is pretty close to what I did. The day before I went to the hospital, I was in intramural sports, played lots of them. At the particular time, it was winter, so we were playing basketball. I had an **intramural basketball game** probably about 36 hours before I went to the hospital.*

Age groups (at diagnosis)	Supporting quotes
	• *Yes. I would walk a good amount, just because I had to for work, but I didn't have a workout regimen or anything. Otherwise, I consider myself, at that time,* ***very healthy****.* • *Yeah, so I…without disclosing where I live. So I was in a community, thriving, full-time job for over 11 years, I believe, at that time. Large group of friends. Close family, sisters. Just kind of very, very independent. Yeah, I worked for a non-profit where I was an officer at an agency. So kind of like in a leadership role and…yeah.* ***Thriving, I guess, is the best way to describe it****.*

Abbreviations: XX, personal identifiable information redacted from interview transcripts.

Symptoms

Symptoms	Supporting quotes
Reported by survivors	
Coma/ unconsciousness	• *Yeah, so when I was first diagnosed, I was in a **coma** for about 3 days. And so when I **woke up** and learned about the diagnosis, I didn't really know what to make of it because I was very disoriented from having been unconscious for several days. And I was also extremely fatigued, so I didn't really process it.* • *I don't think I was…I don't know if I was in the ICU. I might have been, though, because I was **largely unconscious.*** • *Once it was diagnosed, within an hour or 2 I'm guessing of being at the emergency room, I was still **unconscious**. Then I was intubated and put in the ICU.* • *I did take the medicine and go to sleep. I did wake up in the night that particular night, and I did vomit a lot. But once that episode was done, I went back to bed, and that's when **I woke up in the hospital 8 days later.***
Fever	• *From there, it turned…it got worse within…The timeline is a little hard for me to be exact, but within like another 12 hours of those 3 symptoms, it led to **fever**, and it led to the muscle aches getting worse. Then, from there, it turned into vomiting, and then even further down the road, it led to me having such bad leg pain that I wasn't able to stand on my own, which led my mother to call 911 and take me to the emergency room.* • *I had a floppy neck. I couldn't control my neck. I had a very **high temperature**. I think I might have been vomiting as well. I had sent paperwork to XX from that time that mentioned all of these. I don't know if you have a copy of it in front of you or anything.*
Vomiting	• *I don't know. Did I mention vomiting? I was just very sick. Yeah. Like I was just super, super sick. I think that was much later, like in the middle of the night.* • *So, I had persistent **vomiting and nausea**. A kind of blotchy **purple rash** all over my body. The coma that I mentioned, and then heart failure, liver failure, kidney failure, and blood sepsis.*
Neck stiffness	• *I had a headache, **stiff neck**, coughing, runny nose, and fatigue. I was really tired, and nausea.*
Headaches/migraines	• *I had a **headache, stiff neck,** coughing, runny nose, and fatigue. I was really tired, and nausea.*

Symptoms	Supporting quotes
	• *But it was either sinus, and/or **headache pressure** kind of stuff, and then just kind of cold-like. I mean, I really thought I either had the flu or some sort of severe sinus infection.*
Flu-like symptoms	• *The first symptoms were all **flu-like** in nature. I had cold sweats, feverish, body aches, some mild nausea, all flu-like symptoms. The next morning, I woke up and I had purpura fulminans, the little purple spots on my arms and legs, and I had pins and needles pain in my feet when I tried to walk.* • *It was vomiting, but it wasn't initially vomiting, it was just kind of **flu**. It was in February, the month of February, so it was sort of flu and winter season. It felt like the flu. And the vomiting would have been consistent with the flu as well.*
Skin rashes (bruise)	• *My legs, at one point, weren't working. I had a **purple, blotchy rash all over my body**. It was very scary.*
Itchy throat and runny nose	• *The first symptom that appeared was an itchy throat. That was the absolute first thing, was the itchy throat, which over time led to a runny nose and very light muscle ache. Those were the first 3 symptoms.*
Facial muscle paralysis	• *Because I had some paralysis in my cheeks where I couldn't really smile or talk correctly, because my facial muscles weren't working correctly. I believe it was like the left side of my face that had all of that temporary paralysis. That was corrected through therapy at the hospital.*
Reported by caregivers	
Fatigue, fever, unconsciousness	• *He came home a little bit early, and we were really shocked to see him home so early. He said he just didn't feel well. Was really **tired** and his stomach was bothering him, so he came home. Then a few hours later started **vomiting**. Everyone said, "Oh, there's a stomach bug going around. He probably caught it on the way home. It takes a few days to resolve. Yes, it's normal that he's throwing up and having a **fever**"…finding him **unresponsive** gutted me. I still have nightmares.* • *They advised me that he was most likely a teething baby and that the low-grade **fever** and the **tiredness** and fussiness was most likely attributed to that…He saw my son and immediately knew that he had a **purpuric rash** and that he was critical. And so he said, "Your son is very ill. I'll be right back with some medication." He immediately came back and said, "This won't hurt him if it's viral. If it's bacterial, it might help save his life." Then they called the Life Flight, which is the airplanes or helicopters that come. Because we're a very rural area. Then about 20 minutes later, they*

Symptoms	Supporting quotes
	said…they came back in and said, "We can't get an IV started." So they were desperately ***trying to resuscitate*** *[survivor].*
Flu-like symptoms, nausea, skin rash (bruise)	• *The…late afternoon before he was hospitalized…he started to feel…He said, "I felt a shiver go up my spine". He started to feel really* ***cold and nauseated****…By that point, he had the* ***purpura, the purple dots covering his limbs****…That doctor said she asked him when the purple rash had started, because she said if it had come on slowly, it might have been liver failure or kidney failure. But when he said it had come on overnight, she was pretty sure that he had bacterial meningitis. She told the nurse to call a land ambulance and take him to the local hospital. That's when it all got even worse.*
Numbness	• *He said about 5:00 in the morning, he was very parched. The kitchen was like 2 stories down, so he walked down there and got a glass of orange juice. He said on the way back to his room, he couldn't feel his feet. It was like they were…You know when your feet go to sleep and you get pins and needles? But he said he never got the pins and needles feeling. It was just that heavy, "****I can't really feel my feet****."*

Abbreviations: ICU, Intensive Care Unit; IV, intravenous; XX, personal identifiable information redacted from interview transcripts.

Experience with care and treatment at IMD onset

Diagnosis

Experience with diagnosis	Supporting quotes
Reported by survivors	
Experience with diagnosis	• *I feel like it was really* ***difficult for me to get into the doctor*** *and for my mom…My mom really had to advocate for me to get in. She's told me stories about one time…This was the final doctor visit before they said, "Okay, this is a problem." She looked at the doctors and told them, "There is something wrong with my child and I need you to fix it." Sure enough, I had several MRIs, and they couldn't find what was happening. Then finally, after she put her foot down, they found it.* • *Yes. Well, upon arrival at the hospital, they initially* ***thought that I had overdosed*** *on drugs. Probably heroin I've never seen or done heroin. But the way I was brought in, in the condition I was in, that's what they suspected. That couldn't be further from the truth.* • *Yes. I was hospitalized many times, them trying to figure out. Then it was a constant* ***sending me home because they couldn't find the problem****. They pretty much told me that I just need to suck it up, that I'm just being a child…a regular child that makes pain up. But several emergency room trips. I did take only 1 ambulance ride. But several emergency room visits.*

Abbreviations: MRI, Magnetic Resonance Imaging.

First experiences with hospitalization

Hospitalization and emergency department visits	**Supporting quotes**
Reported by survivors	
Hospitalization and emergency department visit	• *And so, when I woke up and learned about the diagnosis, I didn't really know what to make of it because I was* ***very disoriented*** *from having been* ***unconscious*** *for several days. And I was also* ***extremely fatigued****, so I didn't really process it.* • *Probably the first thing that I noticed, of course I* ***woke up in the hospital*** *and I didn't know where I was. I didn't know how I got there, how long I'd been there or anything like that. There was a tube in my nose. I didn't have control of most of my muscles. I was* ***laying down****. So, I'm kind of* ***in shock*** *as to what's happening.*

Interaction with HCPs

Interaction with HCPs	**Supporting quotes**
Reported by survivors	
Negative experiences	• *When I started getting sick and she said, "I think my baby has meningitis." The **doctor basically treated her like she was crazy**. In fact, he told my mom's friend that she was being an overreactive mother. This was before the age of HIPAA so he could say that. That delayed my medical care by, if not hours, days. They never gave me steroids or anything because it was…I don't know. Not really protocol everywhere in the '80s.* • *Apparently, one of the **nurses mixed up**…or maybe one of the doctors mixed up my feeding tube and my breathing tube early on, so that was unfortunate. But I was not conscious for that, so I don't know for sure.* • *A friend of mine is the one that found me and was with them when I got to the hospital. They were trying to understand what it was, and **they were telling them that it wasn't anything drug related**.*
Positive experiences	• *Yeah, so **my doctors were beyond incredible**. They credit my twin and my sisters for my recovery, because of my support system, especially my twin sister. But the doctors, the one who knew exactly how to treat me within minutes of finding out, for my survival. Without that, my initial infectious disease doctor, I would not have survived. Then just the doctors that were my doctors ongoing, up until they all retired, to be honest with you, they all allowed me to stay on their caseload, even though that isn't always the case.* • *I had **amazing doctors, and I am blessed** compared to some people that didn't even get to survive the disease. I had an emergency room doctor that I had taken my son for something, and he asked me what happened, and I told him I had meningococcal, I had bacterial meningitis as a baby he actually asked me if he could hug me because he had never…He said he had worked in an emergency room for 30 years and never saw a baby leave that had meningococcal. He had never met one that survived, so I realize that. I guess that's something that I was always taught to be grateful.* • *For the most part, nearly all of the **nurses were great**. The nursing staff was incredible. Dietitians were great. Physical therapists, occupational therapists were great. I had extremely high-quality care. I mean, I think the proof that I got good treatment was that I survived, you know? I was very touch and go. I was in septic shock. I had disseminated intravascular coagulation. All the medical literature suggests that no matter how good the treatment you get is, you're going to die half the time*

Interaction with HCPs	Supporting quotes
	when you have that. So the fact that I survived means that at least in the critical care period they did pretty much everything right. I can't really complain about the treatment I received. I would say it was probably 90% positive. • *I would say, overall, it was **very good**, all things considered. I understand that it was very unlikely that I would even survive, so I think the fact that I was not only able to survive but made a full recovery is a testament to the level of care that I received.*
Mixed experiences	• *It was a **mix in terms of my interactions with the medical system**. Some of them were extremely positive. A few were pretty negative. There were some doctors that had great bedside manner and others that had very poor bedside manner.* • *I mean, there's a lot of notes and things that were taken about doctors and things that had happened. I do know that the initial doctor that was in charge of me **was not optimistic at all about my chances of survival**. That doesn't align with me personally, but particularly at the time didn't align with my parents who felt they needed a better more optimistic approach to things. So they actually fired the doctor and got a **new one that had a little better approach to things**.*
Reported by caregivers	
Negative experiences	• *He [Survivor] said the last thing he remembered was looking up at the nurse on that flight and asking her if he was going to die and **she wouldn't answer** him. Then he started to say the Our Father and the Hail Mary and he couldn't remember the words. He said that's the last thing he remembered for weeks.*

Abbreviations: HCP, healthcare provider.

Treatment and healthcare resource utilization

Tests and treatments	**Supporting quotes**
Reported by survivors	
Lab work/biopsies/scans	• *Yes. After going to the emergency room, they did **blood work**, but they also did **a biopsy**, a spinal tap.* • *Sure enough, I had several **MRIs,** and they couldn't find what was happening.* • ***Blood checks**, scans, a ton of testing. They were eventually going to do a spinal tap.*
Medications (antibiotics, pain killers)	• *Pretty much close to that whole stay in ICU. I would say probably 20 days, maybe 21. I received an **experimental antiseptic drug** called Xigris, X-I-G-R-I-S. No longer on the market. At the time, it was in clinical trials for sepsis care. I got that too. I got blood transfusions. As far as other treatments, I mean, I had…Most of my hospital stay was in the burn and wound unit, where I got daily or almost daily debridement treatments, which is where they cut off the dead tissue from my arms and legs.* • *One of the first things they did was give me an IV. Then, they catheterized me. Then, they started taking me around for checks. Blood checks, scans, a ton of testing. They were eventually going to do a spinal tap; however, they gave me like **4 different antibiotics**, and 1 of the doctors said, "You know what, you don't need to do the spinal tap, because one of these antibiotics that she's on would cover the meningitis anyway, so there's no need to do the spinal tap".*
Amputations	• *Since then, because of the kidney failure and I **lost both my legs and most of my fingers** and the skin grafts and everything, I've had many, many surgeries. Like I'm not even exaggerating, over 100 procedures.* • *They amputated all **10 of my fingers** and they **amputated both of my feet.***
Surgeries and grafts	• *And I had, believe, **at least 8 or 9 surgeries** while I was in patient there. I had amputations of all of my toes and 9 of my fingers. I had surgery for skin grafting. I had lots of inpatient physical therapy and occupational therapy when I wasn't either in surgery or recovering from surgery.* • *I was in bad shape. I can tell you that my arms and legs, my entire body was black, and they had…A plastic surgeon happened to be…one of my doctors as an infant who was there and immediately had started to try to **wrap my arms and legs in***

Tests and treatments	Supporting quotes
	cadaver skin *to save my extremities, and I believe that was probably some of the process that took a while.*
Rehabilitation and therapies	• *I had some* ***mouth therapy, front throat therapy, swallow treatments****, and things from the ventilator. Plus, there were some issues where I had some neurological things that weren't working correctly, particularly swallowing.*
Nursing services	• *Nobody was coming into the home. Well, I shouldn't say that. At times, I needed IV antibiotics, and yes, the* ***nurse*** *would come into the home to administer the* ***IV antibiotics****, but other than that, I was not receiving home care.*

Abbreviations: ICU, Intensive Care Unit; IV, intravenous; MRI, Magnetic Resonance Imaging.

Short-term impacts on survivors and their caregivers

Journey since IMD diagnosis

Terms used describe journey since diagnosis	**Supporting quotes**
Reported by survivors	
Worst experience/ massive obstacle	• *It was definitely the **worst experience of my life**. It was definitely very transformative because it was such a **massive obstacle** in my life that I had to very much reimagine how to live in order to get past it. And come to a new understanding of who I am, as well.*
Struggle	• *That has really been a **lifelong struggle**. I would say starting as young as like 3.* • *Yeah, I would say it's definitely been a journey. Not just for me, but for my support system, especially my identical twin sister and 2 other sisters. My sister was also my kidney donor. So, it's been a lot of work and **a lot of day-to-day struggles**, I would say.*
Arduous/exhausting/lot of work	• ***Arduous. Exhausting**. I'll be honest, exhausting. Maybe like life affirming.* • *Yeah, I would say it's definitely been a journey. Not just for me, but for my support system, especially my identical twin sister and 2 other sisters. My sister was also my kidney donor. So, it's been a **lot of work** and a lot of day-to-day struggles, I would say.* • ***A lot of work**. [laughs] **Just a lot of work**.*
Difficult	• ***Difficult**, life changing, monumental. I don't know. Hard.*
Life-changing	• *Difficult, **life changing, monumental**. I don't know. Hard.* • *Oh, my journey. Well, it definitely **changed my life** as I was just going through some things there.* • *Oh, **everchanging**, everlasting, **life-changing, life-altering**, scary. Rare, I guess. After knowing about it, it's rare, yes.*

Short-term impacts on survivors and their caregivers

Immediate/short-term impacts	**Supporting quotes**
Reported by survivors	
Difficulty with functional/daily activities	• *On top of the other, what turned out to be more temporary things with the feeding tube and **swallowing and standing and sitting**, and essentially, I had to learn how to do a lot of just **normal functional things**. I couldn't sit up in bed. I couldn't stand. I **couldn't walk. I couldn't talk**. I had to do therapy on my facial muscles to make words. My eyelids themselves actually were not opening and closing correctly. So just through lots of physical therapy at the hospital, some of those things corrected themselves. Some of them did not.*
Needing assistance/ relying on others	• *I was basically completely bed ridden. When I did leave my bed, I had **to lean on my parents**, one of my parents, to be able to walk or else I would kind of crawl on the ground because I wasn't strong enough to walk on my own power. When I did leave my bed, it was to lie on the couch, and…**fully dependent on everyone else in my life for basically everything**.*
Emotional impacts	• *I remember that night very vividly, how I felt and what happened. Let's see. I was definitely **very scared** because I had no idea what was going on.*
School impacts	• *I did. I **missed the last 2-3 months of fifth grade** and the first half of sixth grade. But I did some testing while I was in the hospital, and I was able to go back in. So, I didn't actually lose any time.*
Financial impacts	• *But I think most of the medical necessary stuff, I would say at least 90% to 95% of that was covered by the insurance plan.*
Reported by caregivers	
Physical impacts	• *I could not go to **sleep** at night without seeing him unresponsive again and vomit everywhere. It's just, that was all I could see. So that was really, really hard. I was going…* • *After running up and down stairs, and taking care of him the day before, I was pretty **exhausted**.*
Emotional impacts	• *The doctor said that he will only lose some fingers and toes. **Our reaction was obviously terror.***

	• ***It was very scary**. I was 23 years old and by the time we knew something was seriously wrong and called 911, he had the purpuric rash starting.* • *Like I said, in the beginning, it was really, **really, really taxing.** I'd stay up most nights researching and Googling and trying to figure out if I was making the right decision.* • *He was [hopeless] that day. I just put my arms around him and said, "We couldn't let you die. We loved you too much."* • *We were told he was not going to survive the…whatever process was going on with his body. I remember…I have very vivid memories of that night in hindsight. But if you ask me to recount it, all I can remember is **just being stunned that it was all happening. In a state of shocked panic**.* • *It was. It was a very **hopeless feeling**.* • *In a few words. **Grueling. Demanding** at times, especially as a caregiver, just because it's a lot of information for 1 person to have to hold and understand so their child survives to afterwards.*
Social impacts	• *It was hard before, even with…like as a couple to do date nights and stuff. Because, again, who watches your kid when they're in full splints and masks and all these things that you've got to just know. When that lessened, too, we could enjoy each other as a couple again and go do a date night or go do a movie or whatever. My mom or his mom could watch and we weren't worried that something…some crisis would happen that I would need to be there as a nurse.* • *We didn't plan on having other kids for a long time, just because we were going so much. I didn't work after he got sick because…Well, we were in the hospital and then traveling back and forth.*
Work impacts	• *I **quit my job** the day he got sick.* • *I took a **leave of absence from work**. There was no way I could think about going back to work or doing anything. So, I wanted them to know that I would not be back next week.*
Care management impacts	• *Well, we were in the hospital and then traveling back and forth. There's nowhere that's going to accept those kinds of schedules. Then **finding somebody to care** for him if I did go outside of the home.* • *No. Not a whole lot. We have just 2 boys. We have a 4-bedroom house. The other boy was away at college at the time. He had his own room. The only thing we did was **move a***

	***bigger bed into his room that we had in the guest room**. Because he's tall, and I wanted to make sure he was comfortable while he was getting over everything.*
Financial impacts	• *We were lucky that my husband's employer continued to pay him for 6 months. We were blessed that my paralegal collected all my old accounts receivable. But, yeah, **it was a strain**. Luckily, I had paid our mortgage ahead over a year…my husband was worried about money, I did take a job. It was a temp job as an auditor for the IRS. I worked nights so that I would be able to then accompany [survivor] and…my husband and [survivor] to his medical appointments during the day.* • *Well, we have to pay…Our local airport's 2-1/2 hours away so we have to **pay for gas** to get there. We drive our own personal vehicle so there's **expenses to maintaining the vehicle and even having a vehicle**. There was a few months there that we were kind of short of transportation, which actually ends up being a problem for a lot of people in this situation. Then **staying overnight** in hotels. Again, mileage and hotel expenses would be reimbursed. We would always have to **pay upfront** and then I'd fill out the **paperwork showing receipts** that we stayed or that we went or did gas fill-ups. Then a few weeks later we would get…So there was always that need to have money upfront, going into every trip. Then food, of course. Babies aren't cheap. Then as he grew up, I mean, airport eating isn't cheap. When you're at the hospital and hotels, delivery and their food services are never cheap. There was **expense always eating**. He needed all his medical supplies where we were going. Like I said, the **car seat and the stroller were both very special** so those were expense…extra. A couple times [survivor] had to work and stuff. So we have had to **pay babysitters** to watch the other 2 while [survivor] and I go.* • *Well, first of all, the fundraiser, my husband and I immediately decided was for [survivor]. It was not for us. We knew that there would be a lot of expenses that [survivor] would incur in the future, like **insurance has very poor coverage for things like prosthetics**. That's for him.*

Abbreviations: IRS, Internal Revenue Service.