

# ROY L. MORRIS, ESQ.

■ PO Box 100212  
■ Arlington, VA 22210  
■ 202 657 5793  
■ 509 356 2789 (Fax)  
■ [Roy\\_Morris@alum.mit.edu](mailto:Roy_Morris@alum.mit.edu)  
■ Member of the Bars of the:  
District of Columbia and  
United States Supreme Court

January 28, 2011

Honorable Vincent Gray  
Mayor of Washington, DC  
Executive Office of the Mayor  
1350 Pennsylvania Avenue, NW, Suite 316  
Washington, DC 20004

## **Re: Less Than 18 Hours Until the Avoidable Death of a Child in Washington DC**

Dear Honorable Mayor Gray,

As little as eighteen hours is all the time that the District of Columbia has to take action to save a seven-year-old girl, Ariana-Leilani (“ALM”) living in Ward 3 (Georgetown/Palisades area). ALM is suffering from a misunderstood condition of a very rare blood disorder that causes severely low immunity referred to as “Severe Chronic Neutropenia (SCN).” Now she is one of only 1300 people in the last 16 years worldwide who is on the *Severe Chronic Neutropenia International Registry (SCNIR)*. [See, recent January 25, 2011 Letter of Prof. Dr. Dale, attached]

Eighteen hours is the time it takes for the “clandestine” infection to begin to work itself outward, perforating the gut and ultimately leading to death. If an SCN patient is lucky enough to be “saved” from death, she is likely to still suffer loss of her limbs from the damage done by the infection. This is not a matter of opinion, but comes from two top leading SCN authorities, and founders of the only risk reducing treatment, Professor Dr. Dale and Professor Dr. Welte, the Co-Directors of the Severe Chronic Neutropenia International Registry. [See, attached letters from Dr. Dale and Dr. Welte]. Both world experts have volunteered their time and expertise to help fight for the life of ALM. Professor Dr. Dale and Professor Dr. Welte have reviewed all of ALM’s medical records (2005 until present, including the most up to date records). [See, Graph done by the SCNIR attached to the January 25, 2011 Letter of Prof. Dr. Dale]. ALM’s medical data shows the continued deterioration of her condition. Prof. Dr. Dale and Prof. Dr. Welte, as well as many other experts, have expressed shocked and cannot understand the apparent failure of the various “safety net” systems in Washington, DC to help ALM, including the Key School/DCPS, medical services, police, health services, child welfare, and other institutions.

*With an international child, such as ALM (who holds German citizenship) and the institution’s failures to take appropriate actions, Washington DC may face another Benita Jacks-type case of international proportions. As with the Jacks case, the stark facts are staring the city’s administrators in the eyes yet they have not done effectively anything to help her. Their inaction is partially out of ignorance and partly out of obduracy. With this letter, our hope is to avoid a Jacks-type situation with this direct appeal to you based on the accompanying recently updated information. On behalf of this child, we respectfully ask you as the newly installed Mayor of Washington, DC, to assure that proper measures are taken to assure that this child – who is under the daily care of the city at the Key Elementary School -- is properly protected.*

The US State Department has told the German Embassy in Washington DC, in response to the Embassy's call for help for German citizen ALM [*See, August 17, 2010 Letter of German Embassy to the US State Department, attached hereto*], it is up to the city of Washington DC to save ALM's life, and assure she is given immunity boosting GCSF medicine, independent comprehensive medical examination and attention, and that she is isolated from the source of the abusive "toxins"/drugs that are likely causing her SCN [*See, attached letter from Prof. Dr. Welte*].

### **Background on Severe Chronic Neutropenia (SCN)**

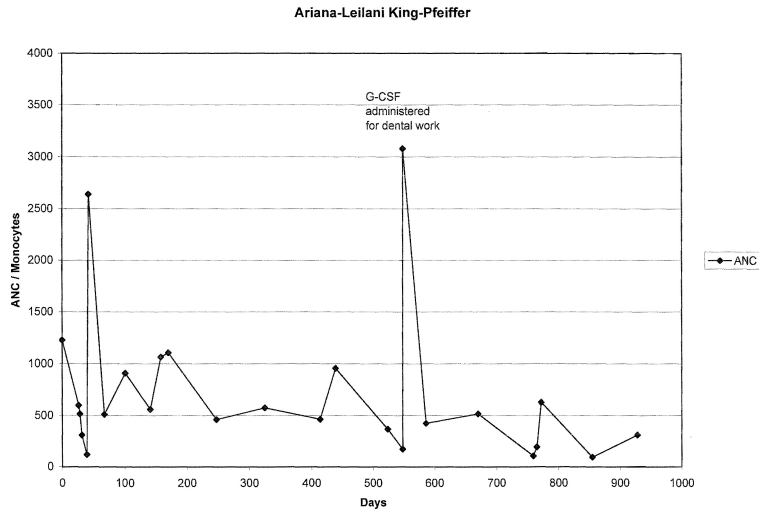
The rare person with Severe Chronic Neutropenia (SCN) has a very low neutrophil count (measured as "Absolute Neutrophil Count," or the "ANC"). SCN occurs when the patient's ANC drops to about 500 or less, (compared to a normal range of 3500 to 5800) for an extended period of time. ALM's ANC has been at that dangerously low level for over two and a half years, and *continues to drop!*

Low ANC not only means that the body has an inadequate number of neutrophils to fight infection, but it also means the patient is unlikely to show the normal outward signs of infection (e.g., lack of fever, muted fever or even a drop in core temperature) [*See January 25, 2011 Letter of Prof. Dr. Dale, attached*]. SCN infections typically occur *internally*, usually, in the digestive tract and *often with no outward signs*. Unfortunately, most physicians, including some at leading medical institutions, see very few patients with this rare condition and don't realize this fact. Teachers, of course, are even more ill equipped to pick up the muted signs, if any, of internal clandestine potentially fatal infections. The SCNIR, which sees and consults on hundreds of SCN patient cases, has been on a campaign to educate and inform physicians about the hidden dangers of the rare SCN patient. SCN patients, like ALM, who show signs of gingivitis and/or sores in the mouth, are likely to have an infection in their gut. The internal infection can result in the perforation of the gut. Because of the lack of the typical warning signs and the basic misunderstandings of the condition in the medical community, SCN patients, even when closely monitored by a physician, have been known to bleed to death within 18 hours without the family or physician realizing early enough the fatal progress of the clandestine infection [*See, attached article in Neutropenia Network Newsletter describing the death of 3 year old Joelle, an SCN child who died because doctors refused to give her prophylactic protection medicine – leading to her death even while under medical care within hours of appearing well*]. Even where the family and physician are vigilant enough to spot the clandestine infection early and stop the bleeding in the patient's gut, the infection still is likely to have made it to the SCN patients' extremities, often requiring amputation of limbs due to gangrene. *Thus, the only risk-minimization approach is try to avoid the condition altogether by prophylactic administration of GCSF medicine to the SCN patient, thus preventing the otherwise negative outcome of "toxic shock, loss of limbs or loss of life"* [*See, Letter of Prof. Dr. Dale*].

Using ALM's Complete Blood Count data from Georgetown University Hospital, the SCNIR made the ANC graph that accompanies Prof. Dr. Dale's January 25, 2011 letter [*see, attached*]. As you can see, her ANC continues to decrease and is now dangerously *below 500 and continuing to drop*. Despite this downward trend to an even more dangerous situation, the DC health officials, including her relatively inexperienced Georgetown physician, *have not* insisted that ALM be given GCSF before she is allowed to attend school. Her condition has been misleadingly labeled as "benign chronic neutropenia." However, as explained by Prof. Dr. Dale, "benign" only means, "not caused by cancer." "*Benign*" *does not mean "harmless."* This mislabeling of the SCN by the inexperienced GUH doctor and the failure to require proper prophylactic treatment before ALM is allowed to attend school sets up DC officials for being responsible for the likely, otherwise avoidable, death of 7 year old ALM.

Certainly, in addition to the negative international attention for DC, a failure to act to prevent harm and/or death – given these clear warning signs -- would bring about potential civil and criminal liability for not only the city, but also its officials. It is ALM's mother, Dr. Ariel

King’s, intentions of directing this information to you in the hope that it will cause DC to consult directly with the SCN experts at the SCNIR, take timely corrective action to save ALM, and, in turn, avoid problems for the city and its officials. Unfortunately, Dr. King does not speak for her estranged husband, Dr. Michael H. Pfeiffer (who has no expertise in this area), who lives at 4836 Reservoir Road in Washington DC with the child. *Dr. Pfeiffer’s actions and words are setting up Washington DC and Georgetown University Medical Center to take the full blame for an adverse outcome, which he can then capitalize upon.*



**Figure 1: Chart of Worsening Low ANC Condition Over Last Two and a Half Years**  
**[Last data point is for November 30, 2010] From January 25, 2011 Letter of Dr. Dale**

The DC Key Elementary School is aware that ALM has had a history of mouth sores, vaginal infections, and gingivitis. Yet, because the school has been misinformed, no alarms were sounded, even though the presences of these symptoms were likely indicators of internal infection. Furthermore, even though urged by the SCNIR world SCN experts through their letters which have been provided to the school and DCPS on several occasions, the DCPS has refused to insist that, as a precondition to attendance at school, GCSF be administered to avoid potentially fatal clandestine infection and its consequences while ALM is at school, or even that an independent medical examination be given to get a second opinion on what needs to be done. The Key School is relying on a *one and a half year old*, out of date, undated, and *inaccurate* "note" from a Georgetown hospital physician, who is much less experienced in this area than Prof. Dr. Dale and Prof. Dr. Welte. [See, attached undated "To Whom It May Concern" note] The misleading note is not reflective of the continued deterioration of ALM’s condition in the intervening one and a half years. It is gross negligence for the school and DCPS to rely on such an undated and out of date note. Furthermore, the “note” is misleading as it inaccurately tells the school that it need only look for the normal signs of infection (fever, rash, or “other symptoms of illness,” etc.) – but, as noted by SCNIR’s Dr. Dale January 25, 2011 letter, those outward signs of infection are not always present or as pronounced as they might be in a child with SCN.

Just like the now deceased Joeline, on any given day ALM could “look like a healthy child.” She could behave perfectly “normal” when she goes to the Key Elementary School in Washington DC in the morning, but by the end of the school day, she may have less than 12 hours left to live. In her current life-threatening untreated medical condition, without proper

prophylactic measures of GCSF, ALM is a “ticking time bomb” and a serious liability for all of Washington DC’s government “protection” agencies and its employees, including the police, the public school system, the Health Services, and the CFSA.

**DC “Safety Net” Institutions Have Thus Far Failed To Recognize the Dangers of ALM’s Untreated Severe Chronic Neutropenia and to Fully Investigate the Cause -- Drugs**

Below is a brief review of the DC institutions that have failed to help ALM (more information can be provided upon request):

- a) ***CFSA failed to act on four detailed medical neglect and abuse complaints made by mandated reporters to CFSA during the Post-Caplan-Case 2008-2009 years of the Mayor Fenty administration (a period when – data clearly shows -- CFSA avoided finding abuse or neglect in Ward 3).*** In the 2008 medical neglect complaint case, even though CFSA required that ALM be taken to a hematologist/oncologist for evaluation because the child’s father neglected to do so, they found the case “unfounded.” Oddly, rather than following the *LaShawn Court* protocol of having a CFSA social worker take ALM to Children’s National Medical Center for examination, CFSA allowed the father to take ALM to Georgetown University Hospital *by himself*. This was not only a violation of the *LaShawn* protocol, but it allowed the father to exploit his ongoing medical professional relationship with his associates at Georgetown University Medical Center and its staff, of which he was a former member. The GUH hematology/oncology physician the father chose was relatively inexperienced in SCN. That GUH physician had only *finished his residency less than three years before*. He had no peer recognition in the field of this type of SCN condition. CFSA then used the “unfounded” classification as an excuse to avoid doing any follow-up on ALM’s health – which continued to deteriorate with *no corrective action taken*. In 2009, three experts called into the CFSA hotline and directly filed complaints with Dr Roque Gerald, the Executive Director of CFSA, to alert the CFSA to the continuing deterioration of ALM’s condition and the failure of the father to make any efforts to determine the condition’s underlying cause or to allow for GCSF medicine protection. By its own written admission, CFSA outrightly refused to investigate the 2009 medical abuse and neglect complaints involving the worsening SCN condition. CFSA’s refusal was based on its false claim that that the 2009 complaints (filed with updated information and expanded details) presented "the same set of facts" as the 2008 complaint. Obviously, as anyone can see from the ANC graph, CFSA’s reasoning defied the facts.
- b) ***DCPS Has Missing Medical Records Documenting the Seriousness of the SCN and Has Failed to Act:*** Medical information has been presented to DCPS concerning the facts and the inherent dangers of ALM’s untreated SCN condition and the inherent potential for her suffering from a fast moving clandestine fatal infection while attending the Key Elementary School or any other DC Public Schools (DCPS). Those materials included a copy of the Severe Chronic Neutropenia Handbook, complete copies of her medical records, and the letters of the SCNIR SCN experts. This information was provided to DCPS multiple times. However, based on two FOIA requests to DCPS, *that critical warning information appears to have been removed from the ALM’s school medical file*. The DCPS has taken no preventative action, and the staff’s are not being properly kept informed to avoid the unnecessary risks of infection for ALM.
- c) ***German Embassy Demands Action, but US State Department Says It Is Up to Washington DC to Act:*** Innocence in Danger International (an International NGO), and Professors Dr. Welte and Dr. Dale Co-Directors of the Severe Chronic Neutropenia International Registry (SCNIR) have all contacted and appealed to the German Embassy, calling for action to provide ALM safety [*ALM is a German child, living in Georgetown/Palispades with her German father.*] Dr. Welte’s letter pointed out the likelihood that the SCN is toxin /drug induced – which can be drugs of the type used to

enable undetected child abuse and which are often overlooked by physicians and CPS agencies. [See, *Yin, Dr. Shan, MD, MPH, Malicious Use of Drugs in Children, The Journal of Pediatrics, November 2010*] Dr. Dale pointed out the critical need for GCSF. In turn, the German Embassy formally wrote to the US State Department to get ALM the needed medicine and independent medical/psychological attention she needs. [See, *attached August 17, 2010 Letter from the German Embassy to the US State Department.*] However, the US State Department responded to the German Embassy stating that only the government of Washington DC can give ALM the safety she needs.

- d) ***Mayor Fenty's CFSA General Counsel James P. Toscano Intentionally Interfered with the DC Courts Taking Action:*** In April 2009, ALM's mother Dr. King (who lives in Germany) filed a medical neglect complaint in the DC Superior Court accompanied by an affidavit of a hematology/oncology expert with 35 years experience. The Judge would not let that expert testify even though she acknowledged he was a hematology/oncology expert, but not a "pediatric hematology expert." Aberrantly, CFSA's General Counsel, James P. Toscano intentionally showed up at two of the hearings (without being either subpoenaed or court ordered to be there), apparently at the demands of the father and/or his attorney (who were the only parties he engaged in conversation with in the courtroom). Mr. Toscano then inserted himself in that private litigation matter (on DC City payroll time) and demanded an ex parte with the Judge in her chambers, where, based on information he subsequently filed with the court, he told the Judge that CFSA had not found medical neglect – even though later on he admitted CFSA had not done an investigation of the SCN matter in 2009 (see above). Based on Mr. Toscano's misrepresentations to the court, the Judge denied the request for an independent medical examination in that private civil case. An appeal of that decision is pending, and a decision should be rendered within the coming weeks.
- e) ***A Conflicted DC Medical Board – Composed of Medstar Affiliated Physicians – Refuses to Force Georgetown/Medstar to Take Proper Actions:*** Dr. King, on behalf of her daughter, ALM, filed complaints with the DC Medical Board in 2009 against Georgetown University Medical Center and the GUH physician for failure to meet the standards for the practice of medicine, and not keeping accurate medical records. Despite extensive documentation supporting the complaints, the DC Board of Medicine refused to act without even investigating the merits of the complaints. Their failure to act is explained by the board meeting minutes that showed that the members of the DC Board of Medicine who work for MedStar owned and affiliated institutions actively sought to have those complaints dismissed, and thus avoiding potential liability for Medstar.

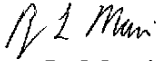
*Rightly or wrongly, the US State Department has squarely placed on the Washington DC government the international responsibility to protect the life of this German –American child who lives with her German father in Washington, DC. This responsibility cannot be shrugged anymore, nor fingers pointed elsewhere as the Police, DCPS, Department of Health Services, CFSA, and other agencies have done in the past.*

Today, ALM attends the Key Elementary School, yet could be at any time only 18 hours away from her death.

You are respectfully being requested to use this opportunity to exemplify your vision to “expand our moral conscious.” ALM expects that Washington DC's institutions and its dedicated employees will protect her from unnecessary risks and even her otherwise avoidable death. As President Obama said when speaking of the 9 year old visionary Christina Green's tragic death, at the side of targeted Congressman Gabrielle Gifford, *"All of us - we should do everything we can to make sure this country lives up to our children's expectations."* That would apply to ALM's expectations, too. Regardless of the work that ALM's father is doing for the US military in Washington DC, ALM still has a right to be healthy and protected.

Please let me know within seven days what actions the Washington DC government is going to take to correct this situation. A meeting with you and your staff to discuss this matter is also requested. Also, please do have the Washington DC Government educate itself on the hidden dangers of ALM's SCN by directly contacting either Prof. Dr. Dale or Prof. Dr. Welte at the SCNIR. After I receive your timely response, I will report that information back to the US State Department and the German Embassy to allow them to determine what, if any, additional steps we must take to get ALM the protection she needs and has been denied until now.

Sincerely,

A handwritten signature in cursive script, appearing to read "Roy L. Morris".

Roy L. Morris, Esq.

Cc: Dr. Ariel King (Mother of Ariana-Leilani King-Pfeiffer)

**David C. Dale, MD**  
Professor of Medicine  
**Audrey Anna Bolyard, RN, BS**  
Research Nurse

January 25, 2011

The Honorable Klaus Botzet  
Consul General and Legal Advisor  
Embassy of the Federal Republic of Germany  
4645 Reservoir Road NW  
Washington, DC 20007-1998

Michael Regan  
Director, Office of Children's Issues  
U.S. Department of State  
220 C Street N.W., SA-29, 4th Floor  
Washington, D.C. 20520

RE: ALM [REDACTED]  
German Passport No: ALM [REDACTED] (per mom, Dr. Ariel King)

Dear Mr. Botzet and Mr. Regan:

I am writing on behalf of ALM [REDACTED]. The Severe Chronic Neutropenia International Registry (SCNIR) has received the laboratory reports for ALM [REDACTED]. The graph of the blood work showing the neutrophil count has been included. The median neutrophil count from the 27 blood counts supplied to the Registry from June 20, 2005 to November 30, 2010 is 518 /cmm (the range is 96 to 3526 /cmm). Neutrophil counts would normally range from 1800 to 7000, the median normally around 4000.

Severe chronic neutropenia is a rare condition wherein the bone marrow doesn't produce sufficient neutrophils to keep the levels in the blood above 500/cmm, resulting in a level of neutrophils too low to fight infection. The diagnosis of benign neutropenia is an older medical term, benign meaning not malignant. The current terminology is mild neutropenia (referring to patients that have an ANC between 1000 to 1500 /cmm), moderate neutropenia (patients that have an ANC between 500-1000 /cmm), and severe chronic neutropenia (patients having neutrophils that are consistently below 500 without G-CSF treatment).

Neutrophils are very important because they fight infection. When bacteria invade the body a chemical signal is sent out and the neutrophils, like fire fighters responding to a blaze, rush to the site of infection. The bone marrow also responds by speeding up its production of neutrophils to replace those involved in fighting the infection. If, however, production of new neutrophils is suppressed or slowed down, a shortage may develop, and any infection can overwhelm the few neutrophils available. Therefore, a person with only a few neutrophils is at particular risk for developing a serious bacterial infection.

Because mortality rates associated with untreated bacterial infections in neutropenic patients are high, the rapid treatment of these patients is critical. Severely neutropenic patients may not always be able to mount a fever, inflammation or the typical response to an infection. It is important to stress that while fever often is the sole sign of severe infection in the neutropenic patient, because of this blunted fever response in some infected patients, fever may be totally absent and they may instead exhibit a severe drop in core body temperature, low blood pressure, listlessness, or confusion. Thus, infection must be considered and treated empirically if any signs of clinical deterioration are present in a neutropenic child, regardless of the recorded temperature.

Many SCN patients are treated with G-CSF, a hormone that increases the neutrophil level. This medication helps fight infection by raising the neutrophil count. However, even with the administration of G-CSF, the neutrophils may still drop to critical levels, and while G-CSF allows the patient to fight disease-causing microorganisms better than the untreated patient, infection is still a constant concern. The treated patient will continue to experience infections, but hopefully not life-threatening infections. The neutropenic person's life may be greatly affected by her/his inability to fight infections.

The SCNIR follows over 1300 SCN patients. We have tracked each of these patients, gathering medical information over the last 16 years for the Registry and 7 years before that in clinical trials.

Our mission is to follow closely the health of neutropenic patients and to continue to research the mechanisms causing this condition. The SCNIR is actively distributing information regarding SCN to doctors and patients. The goal is to help the local physician become more knowledgeable about this rare and difficult condition, and to prevent the severe consequences of untreated SCN: Toxic shock, loss of limbs, and loss of life.



If you have any questions regarding neutropenia and/or the work of the SCNIR, the SCNIR web site is very helpful: <http://depts.washington.edu/registry/>


Please feel free to contact me directly at 1-800-726-4463.

Thank you.

Sincerely,



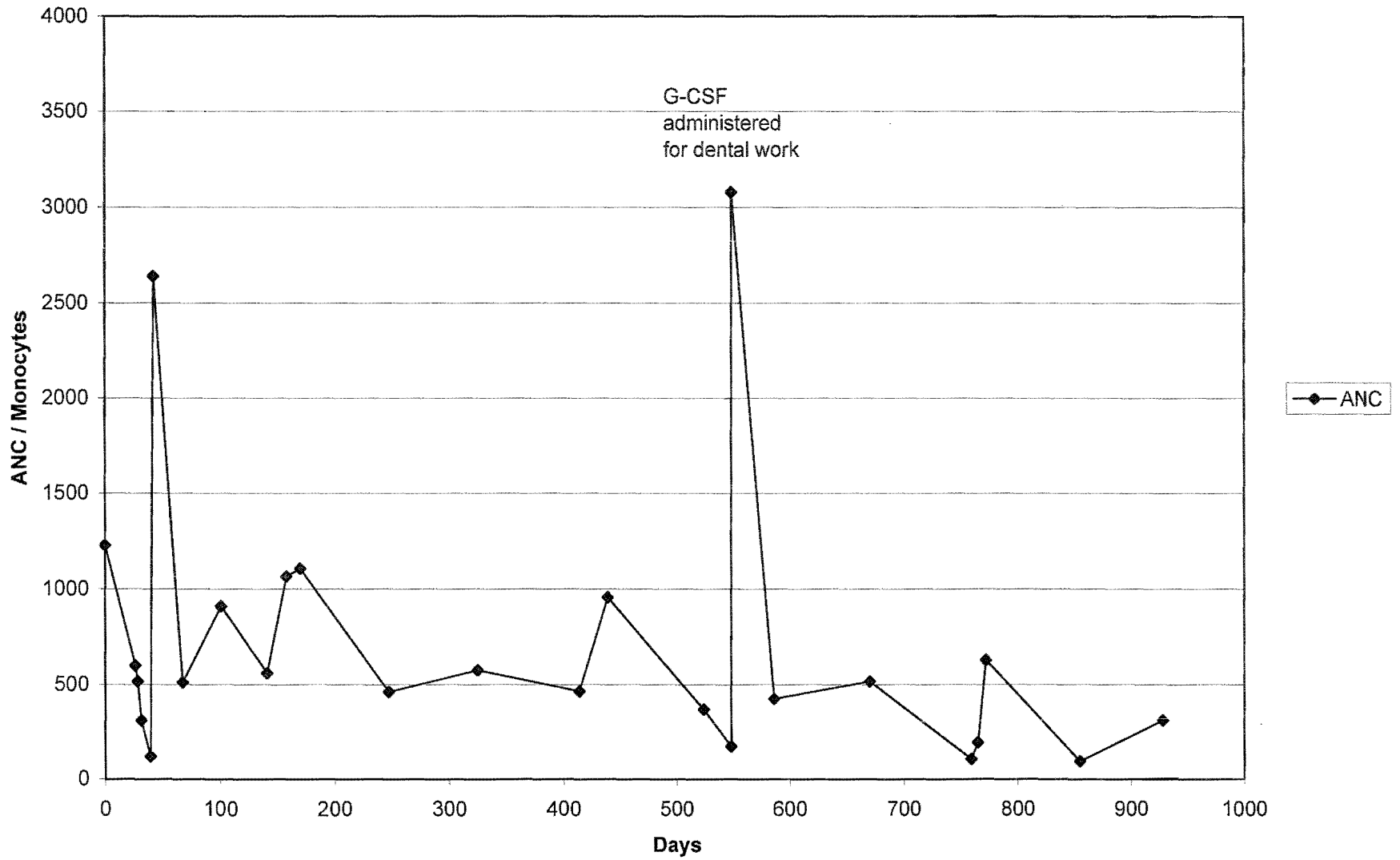
David C. Dale, MD  
Professor of Medicine



Audrey Anna Bolyard, RN, BS  
Clinical Manager SCNIR

DCD/las

ALM





Embassy  
of the Federal Republic of Germany  
Washington

Mr. Michael B. Regan  
Director  
Office of Children's Issues  
U.S. Department of State  
2201 C Street N.W., SA-29, 4<sup>th</sup> Floor  
Washington, D.C. 20520

ADDRESS

4645 Reservoir Road, N.W.  
Washington, D.C. 20007

INTERNET: [www.germany.info](http://www.germany.info)

TEL + 202 298 8140 (Switchboard)  
FAX + 202 471 5558

Klaus Botzel  
Consul General and Legal Adviser

TEL-DIRECT: 202 298 4361

[rk-1@wash.diplo.de](mailto:rk-1@wash.diplo.de)

ALM

Ref. No. (please cite in response): RK 520. SE King-Pfeiffer

Washington, D.C., August 17, 2010

Dear Mr. Regan,

Please allow me to bring to your attention and seek your assistance in the case of seven year old [REDACTED] ALM [REDACTED], a child with dual German and American citizenship. She is living with her father, the German national Dr. Michael Pfeiffer, in Washington, D.C. Her mother, Dr. Ariel King, a U.S. citizen, lives in Germany.

Earlier this year, the NGO Innocence in Danger International has brought serious concerns about possible medical mistreatment and possible sexual abuse of the child by the father to the attention of the Embassy. The concerns related to medical mistreatment, based on the child's extensive medical and school records, and were supported by physicians of the Severe Chronic Neutropenia International Registry and the German NGO Avalon.

The German Embassy so far has had no direct access to the child nor to information from an independent source. As of today, the Embassy has received documentation on the child's case consisting of medical test records from George Washington University Hospital (GWUH), opinions and school health records. Unfortunately, without the consent of the father who has sole custody, the Embassy has no way of verifying the status of the child, or the information it has been given.

In any event the allegations are of such a serious nature that we feel that a fully independent medical examination of the child should be ordered by the competent U.S. authorities. A divorce and custody case is currently pending in Bayreuth, Germany. The mother claims that the father refuses to agree to allow her, or anyone acting on her behalf, to have direct contact with her child, the child's sole treating physician at GWUH, and GWUH itself. The mother is represented by Mr. Roy L. Morris, Esq., Arlington, VA. The father is represented by Mr. Sean W. O'Connell, Arlington, VA.

GWUH health records, which were forwarded to the Embassy, state that the child suffers from Severe Chronic Neutropenia, a medical condition which consists of severely low immunity levels over an extended period of time that leave the child vulnerable to potentially fatal infections. The Embassy was also provided with opinions from international experts in the field of pediatric hematology who expressed serious concerns for the child's safety. In the opinion of these experts there is a lack of a thorough evaluation of the cause of the medical condition of the child and a lack of an appropriate treatment with a medical drug called GCSF which boosts immunity to more normal levels. However, these medical experts have not yet had the possibility to examine the child in person.

The mother believes that the medical condition of the child could have been induced by the administration of a particular psychotropic drug. According to her, the sole treating physician's reports are biased because he is an associate of Dr. Pfeiffer at GWUH, and his reports show inconsistencies with regard to the medical tests and school reports.

The Embassy was informed that Dr. Pfeiffer has been working at GWUH as a physician until 2008. Reportedly he is currently working for the Veteran's Administration Hospital in Washington, D.C.

The report from a guardian ad litem in a past child custody case notes that the child purportedly lives in a one-bedroom apartment with her father. The representative of the mother, Mr. Morris, forwarded documents which include a statement of a clinical psychologist from Maryland who, based on medical records, interviews of the mother, and other documentation, utters her professional opinion in writing that the child ALM "...continues to be at risk in her current environment of both physical and medical neglect, and likely sexual abuse."

The German Embassy has a legal obligation under Art. 5 of the German Consular Act to support German citizens in need of assistance. A written proposal from the Embassy dated March 30, 2010, to let the child undergo a full independent medical examination on a voluntary basis – and which costs the mother's health insurance in Germany would cover - has been declined by the father's lawyer, Mr. O'Connell. So far, the father has refused to communicate with the Embassy directly.

The possibilities of the Embassy are limited to voluntary cooperation and have been exhausted. The German Embassy would therefore be grateful if the Department of State could take up this matter in order to obtain an independent medical examination of ALM King-Pfeiffer. Once her true health status is clarified, optimal medical care for her seemingly serious medical condition can be ensured.

If you have questions in this matter please do not hesitate to contact me. I am including a list of points of contact and a copy of a letter from the University of Washington, Department of Medicine, in this matter for your information.

With many thanks for your support.

Sincerely yours,



Klaus Botzet

**David C. Dale, MD**  
Professor of Medicine  
**Audrey Anna Bolyard, RN, BS**  
Research Nurse

July 9, 2010

The Honorable Klaus Botzet  
Consul General and Legal Advisor  
Embassy of the Federal Republic of Germany  
4645 Reservoir Road NW  
Washington, DC 20007-1998

RE: ALM [REDACTED]  
German Passport No: 875289379 (per mom, Dr. Ariel King)

Dear Mr. Botzet:

I am writing on behalf of ALM [REDACTED] who has been recently enrolled as a participant of the Severe Chronic Neutropenia International Registry (SCNIR) in Germany. The SCNIR was established in 1994 to study the rare condition of Chronic Neutropenia and is funded by the NIH.

Neutropenia is the condition of having lower than normal neutrophils. A normal absolute neutrophil count (ANC) is maintained at approximately 2000-5000 /cmm, allowing a person to fight off infections. Mildly neutropenic patients have an ANC between 1000 to 1500 /cmm, moderately neutropenic patients have an ANC between 500-1000 /cmm, and severe chronic neutropenia is the rare condition where the bone marrow doesn't produce sufficient neutrophils to keep the levels in the blood above the 500/cmm level, resulting in not enough neutrophils to fight infection. ALM [REDACTED] has severe chronic neutropenia; her neutrophils were consistently below 500 without G-CSF treatment.

Neutrophils are very important because they fight infection. When bacteria invade the body a chemical signal is sent out and the neutrophils, like fire fighters responding to a blaze, rush to the site of infection. The bone marrow also responds by speeding up its production of neutrophils to replace those involved in fighting the infection. If, however, production of new neutrophils is suppressed or slowed down, a shortage may develop, and any infection can overwhelm the few neutrophils available. Therefore, a person with only a few neutrophils is at particular risk for developing a serious bacterial infection.

Many SCN patients are treated with G-CSF, a hormone that increases the neutrophil level. This medication will help fight infection by raising the neutrophil count. Even with the administration of G-CSF, the neutrophils may still drop to critical levels. G-CSF allows the patient to fight infection better than the untreated patient, but infection is still a constant concern. The treated patient will continue to experience infections, hopefully not life-threatening infections. The neutropenic person's life may be greatly affected by her/his inability to fight infections.

The SCNIR follows over 1300 SCN patients. We have tracked each of these patients, gathering medical information over the last 16 years for the Registry and 7 years before that in clinical trials.

Our mission is to follow closely the health of neutropenic patients and to continue to research the mechanisms causing this condition. The SCNIR is actively distributing information regarding SCN to doctors and patients. The goal is to help the local physician become more knowledgeable about this rare and difficult condition, and to prevent the severe consequences of untreated SCN: Toxic shock, loss of limbs, and loss of life.

If you have any questions, the SCNIR web site is very helpful: <http://depts.washington.edu/registry/>

Please feel free to contact me directly at 1-800-726-4463.

Thank you.

Sincerely,



David C. Dale, MD  
Professor of Medicine



Audrey Anna Bolyard, RN, BS  
Clinical Manager SCNIR

DCD/las

## TRANSLATION

### Medical School Hanover, Germany

Lower Saxony Professorship – 65 plus Research

Prof. Karl H. Welte, Dr. med.,  
Director, Department of Molecular Hemopoiesis

Center for Pediatrics and Adolescent Medicine  
OE 6790

Phone +49-(0)511-532-6710

Fax +49-(0)511-532-6998

[welte.karl.h@mh-hannover.de](mailto:welte.karl.h@mh-hannover.de)

Carl-Neuberg-Str. 1  
30625 Hanover, Germany  
[www.mh-hannover.de](http://www.mh-hannover.de)

Dr. Kerstin Niethammer-Jürgens  
Am Neuen Garten 4

14469 Potsdam  
Germany

31 August 2009

### Medical Opinion

ALM [REDACTED] born ALM [REDACTED] 2003

Dear Dr Niethammer-Jürgens,

This report deals with the abovementioned patient whose mother accompanied by Ms Hebart-Herrmann with medical records consulted us on 31 August 2009. Unfortunately the child is at present in the USA so that we were unable to examine her in person.

On the basis of the medical documents produced we have arrived at the following evaluation:

#### Diagnoses:

- Severe chronic neutropenia of unknown origin,  
no exclusion of a mutation in the genes *ELA2/HAX1/SBDS*
- To date no indication of an antibody-induced immune neutropenia
- To date no therapy with hematopoietic growth factors

#### Case history (Anamnesis):

For the detailed anamnesis you are referred to the numerous records. According to information provided by the mother, the child developed normally relative to its age until May 2008. There was no unusual increase of infections. In a hemogram during a routine check-up, the primary care physician discovered the neutropenia which was subsequently confirmed. At the time the child was without infection, and there was no indication of an underlying primary disease. The absolute neutrophil count in the majority of findings was under 500/ $\mu$ l.

Further diagnostic investigations to clarify the cause of the severe neutropenia with continuous absolute neutrophil counts under 500/ $\mu$ l were only undertaken in July 2009 at the Georgetown

University Hospital, Washington, by Dr Myers. There was no sign of maturation arrest of granulopoiesis as an indication of a congenital neutropenia. At the same time there was no evidence of a malignant systemic disease. Taking the bone marrow findings and the persisting severe neutropenia together, the most likely assumption is a bone marrow disease caused by an infection or induced by toxic agents.

**Recommendations:**

ALM s suffering from a severe chronic neutropenia of hitherto unknown origin.

In view of the fact that a chronic neutropenia with absolute neutrophil counts of under 500/ $\mu$ l involves the risk of a life-threatening infection, treatment with the hematopoietic growth factor G-CSF, e.g. Filgrastim, should be initiated urgently.

In view of the unknown origin of the neutropenia we recommend that the diagnostic investigation be continued in order to exclude an autoimmune disease, an infectious disease and a malignant systemic disease.

Independent of this we recommend that a bone marrow screening with histology and cytogenetics be repeated in approx. one year.

A conclusive assessment is only possible after personal consultation with the child.

Yours etc.

[signature]

Prof. Karl Welte, Dr. med.

Co-Director SCNIR (Severe Chronic Neutropenia International Registry)



# National Neutropenia

## N E T W O R K

### “EAST COAST”

2007 **SUCCESS!**  
Conference:

*An Action-Packed Event*

The 2007 Neutropenia Family Conference, hosted by the National Neutropenia Network (NNN) and the Severe Chronic Neutropenia International Registry (SCNIR), had its “East Coast” debut in Ann Arbor, Mich., July 6-8. More than 120 people attended the annual conference. Once again, it was a great success.

The Ann Arbor location attracted families from the East and Midwest who have been unable to make the trip to Seattle, though people did come from throughout the country — some as far as California and Texas. Attendees came to share information, learn the latest research and provide support to one another.

The 2007 medical speakers included Laurence A. Boxer, MD, SCNIR chairman and specialist from the University of Michigan Pediatric Hematology/Oncology Department; David C. Dale, MD, SCN specialist from the University of Washington and SCNIR director; Peter E. Newburger, MD, vice chair of pediatrics at the University of Massachusetts Medical School and SCNIR director; and Mary Ann Bonilla, MD, pediatric hematology/oncology special-



The 2007 SCN conference was hosted in Ann Arbor, Mich.

*Promoting awareness, education, research and support for people with neutropenia and their families through a national resource network. A volunteer driven 501(c)3 nonprofit organization.*

ist from St. Joseph’s Children’s Hospital in Paterson, NJ and SCNIR director.

Activities kicked off Friday with a reception and a story circle facilitated by life

coach Trish Robichaud.

Saturday morning began with breakfast and a warm welcome from Lee Reeves, NNN president. Dr. Boxer then expressed his enthusiasm for the having the event in Ann Arbor and

for seeing so many patients who made the trip to learn more about neutropenia. “It is so gratifying as a physician to know that your lives are being changed,” he said. “It was very frustrating prior to the ability to use Neupogen. All we had was supportive care.”

Dr. Newburger was first on the agenda with a presentation on “My Favorite Cell: A brief overview of neutrophil production and function.” This was a new topic for the conference and it got high marks from attendees who were thrilled to hear how this amazing white blood cell performs in the body. Dr. Newburger even included some fascinating footage of neutrophils prowling the blood stream for bacteria to devour.

*continued on pg. 4...*

## Mother’s Tragic Loss Spurs Activism

*“The hardest thing in the world was to leave my baby in that emergency room and get in my car with empty arms and go home to a house filled with toys and sippy cups with no one to use them.”*

Brittany Mothershead has dealt with her own cyclic neutropenia her entire life. Diagnosed at age 2, and having been on Neupogen for a few years as a child herself, she knew what she was battling now with her young daughter.

When Joeli was 2 months old, she landed in the pediatric ICU with no neutrophils and a raging bladder infection. The doctors felt confident in giving the diagnosis of cyclic neutropenia since mom had it too. They agreed to treat the episodes as they came and see how she did. Brittany hadn’t seen a hematologist since she was 12 — treating each infection through other physicians — so she agreed to proceed in the same manner with Joeli.

When Joeli turned three, Brittany wanted to go ahead with the 6-week blood study to document Joeli’s cycle and get her on Neupogen. “They didn’t return my calls. They wouldn’t give me any of the results. They would just tell me ‘Oh, she’s fine.’ I am 24, I know. I know what granulocytes are; I know what lymphocytes are. They wouldn’t listen.”

So, on Thursday, Jan. 12, she took Joeli and the results of the 6-week study to a hematologist in Birmingham, about four hours away from their home in Creola, Alabama. “I begged him to put her on the Neupogen,” Brittany painfully recalls. “She was in school and I was scared. He said she wasn’t sick enough. With that what could I do? I went back home.”

Just two days later, Joeli fell ill and spiked a fever. Brittany brought her to the ER. Her CBC showed no neutrophils; her rapid strep test came back positive — though

*continued on pg. 2...*

### ~ INSIDE ~

- Pioneering SCN .. 3
- “Why Do I Have Neutropenia?” ..... 5
- Mother, Son and Doctor Allies in SCN Fight ..... 6
- Conquering a Lifetime ..... 7
- Parenting/Coping Chronic Illness .. 8

# Letter's From Lee

Quantum leaps in the treatment of neutropenia have been made since my daughter was diagnosed in 1978. The introduction of Neupogen has been by far the most significant. Before Neupogen antibiotics were used to manage the endless infections that plagued Leta's life. I stopped counting her hospitalizations after the 40th. Those were lonely times with no support group to turn to. Now, nearly 30 years later with all the advances in treatment — from the advent of Neupogen to improved bone marrow transplant protocols — I believe the need for our support group is even greater.

The 2007 Family Conference drove this home in a powerful way. In the feedback forms almost everyone stated "education" as one key reason for attending: "to learn about the latest research," "to understand the difference between cyclic and idiopathic," "to learn how to deal with side effects of Neupogen."

When Leta was growing up, these were not issues. The research had yielded little success; the term idiopathic neutropenia didn't exist, and the side effects we worried about were from antibiotics. In this era of abundant information, those who keep current on relevant research findings have the best chance of getting optimum medical care. With four of the leading specialists in the country presenting at this year's event, attendees had access to an unprecedented wealth of information.

One thing hasn't changed in 30 years. People still want to network. That's what inspired many to make the trip to Ann Arbor this past July: to meet others like me, to share my story, to connect with others. Throughout the weekend they laughed and cried together and told heart wrenching stories. They arrived as strangers and said goodbye as friends. The children played in a setting where neutropenia was a commonplace word and taking

...continued from pg. 1

Brittany says she showed no signs of strep throat, no sore throat, nothing. They called the doctor on call and he claimed the infection is what's to blame for the low ANC. He ordered a shot and a prescription of oral Zithromax. "They told me to go home."

On Monday morning, Joeli vomited directly following her first dose of the antibiotic. Brittany called her pediatrician. They said she'd be fine and to make sure she drank plenty of fluids. But on Tuesday, Brittany says Joeli was fussy and lethargic. She took her back to the doctor. "They did not do a CBC. I didn't think to tell him to do it. Tuesday night she vomited green. She didn't want to get up and walk because her tummy hurt. I had to carry her to the bathroom." She called the doctor yet again, and they advised her to take Joeli off the Zithromax.

By Wednesday night things were getting worse. Another call to the doctor, another "if she is drinking, she will be fine" reply. Brittany became frantic on Thursday morning when Joeli's pulse was almost 200 when she checked it. They had been up all night. The doctor said to meet them at the office when they open, but when they arrived they were told the doctor was running late and to take Joeli straight to the ER.

"I was crying, I knew something was wrong. They made us wait when we got there. She arrested at 10:17 that morning, and they couldn't get her back." Joeli had gone septic from a *pseudomonas aeruginosa* infection. The deadly bacteria had infiltrated her bloodstream,

shots, considered normal. They came out of their programs smiling and animated.

The annual conference is a bittersweet experience for me. It calls up difficult memories but it also reminds me that bringing people together to share their stories and celebrate their victories is a perfect way to honor my daughter's life.

This year many people stepped in to help make the conference a success. At the risk of leaving some deserving person out, here are their names: Audrey Anna Bolyard, Tracy Marrero, Kim Blanz, Debbie Dicesare, Mara Lim, Shelly Fiscus, Tammy Loader, Kristen Saleh, Jennifer Schraag, Sharon White, and the many good Michigan friends I persuaded to volunteer for the children's program.

A very special thank you goes to Erin Bogart, a driving force throughout the planning stages and for the entire weekend. Here's an excerpt from a note she sent me that sums up how many of us felt after the final gathering on Sunday: "I can't stop thinking about all the amazing people I met over the weekend. I'm excited to see what we can do with all the new energy created."

In closing I wish to thank Audrey Anna Bolyard and Dr. David Dale for recognizing the need for a Family Conference years ago and for stepping up to host the first one in 2000. They started something big!

*Lee Reeves is the president of the National Neutropenia Network. Her daughter Leta, who passed away in 1997, had congenital neutropenia.*

then her heart and lungs.

"It's taken me a long time to be able to say things happen for a reason. I hate that it had to be my baby, but I will make sure that no child will go to that hospital with no neutrophils" and it cost them their life. "They are going to know my baby's name."

One week later, Brittany had to call to cancel the follow-up appointment with the hematologist. "When I called, I asked if she was sick enough now — because she wasn't here anymore."

Joeli was a vibrant 3-year-old who liked baby dolls and working outside with her daddy. "She liked make believe and she loved school." There are many moments Brittany remembers about Joeli's final weeks, but some are especially poignant. "It was like she had a lot of insight all of a sudden. I didn't notice it at the time. I thought she was like everybody else's three-and-a-half-year-old, but she wasn't."

In her final week, there were many times that Joeli spontaneously told those close to her how much she loved them. She was very loving to her baby sister, Brelan, and her father, Chad. She made calls to her grandparents and other close relatives "just to say she loved them."

Brittany hopes that Joeli's story will encourage other parents to continue pursuing the best care for their children. "I am hoping that I can raise awareness for those in the Neutropenia Network and raise awareness for physicians and parents. I know that this is what the rest of my life will be about."



Shay Jones with Lee Reeves at the 2007 Family Conference

The National Neutropenia Network newsletter is published three times a year.

Editor-in-Chief  
Lee Reeves  
leereeves99@comcast.net

Production editor/writer  
Jennifer Schraag  
nnnewsletter@yahoo.com

*A very special "Thanks" to  
Cyndi Lieske for doing all of the  
writing for this issue*

Comments, contributions, and article suggestions are always welcome and encouraged. Please email Lee Reeves or Jennifer Schraag or write to:

National Neutropenia Network  
P.O. Box 1693  
Brighton, Mich. USA 48116  
(810) 229-5797  
www.neutropenianet.org

## NNN LINKING FAMILIES PROGRAM

The NNN LINKING FAMILIES PROGRAM links individuals with similar diagnosis and life situations.

If you are interested in contacting individuals and families with the same condition you or a loved one is facing, please email Lucy at: [lucyly3@aol.com](mailto:lucyly3@aol.com).



Joeli Mothershead



Georgetown  
University  
Hospital   
Lombardi Comprehensive  
Cancer Center  
MedStar Health

The Children's Cancer Foundation  
Pediatric Hematology Oncology Clinic

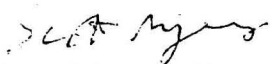
Department of Pediatrics  
Division of Pediatric Hematology/  
Oncology, Blood and Marrow  
Transplantation

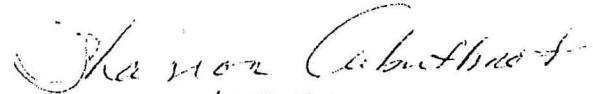
To Whom It May Concern:

I examined ALM [REDACTED] on June 26, 2009 and she may attend school without restrictions. Please be aware of the following recommendations:

1. Good hygiene practices should be encouraged in the classroom including good hand washing and covering mouths when coughing.
2. ALM [REDACTED] should not be seated next to children who have symptoms of illness including discharge from the nose or eyes, fever, chronic coughing or symptoms related to chicken pox.
3. ALM [REDACTED]'s family should call the Georgetown University Division of Pediatric Hematology/Oncology (202-444-7599) if she develops a fever, rash, or other symptoms of illness.
4. ALM [REDACTED]'s father should be notified if a student in her classroom is sick with fever, discharge from the nose or eyes, fever, chronic coughing, or if a student is diagnosed with chicken pox or strep throat or any other infectious disease.

Thank you for your assistance with this family,

  
Scott Myers, MD  
Georgetown University Hospital  
Division of Pediatric Hematology/Oncology  
202-444-0406

  
LICSa  
202-444-1346

Aziza Shad, MD, Director  
Amal Abu-Ghosh, MD

Corina Gonzalez, MD  
Jeffrey Toretsky, MD

Kristen Snyder, MD  
Scott Myers, MD, MPH

Katherine Myint-Hpu, CPNP  
Karen Hennessy, CPNP