

Baby Sharon June 2025 Case Summaries -Can have 10 cases per month and up to \$10,000 total for the month.

Number of cases: **We have 7 cases.**

Total amount requested **The total for the 7 cases is: \$9,850.17.**

May Case Summaries Status Updates-Please see separate attachment

All members of the Baby Sharon Fund Advisory Council were present except Dr. Patrick Casey.

Case #1: This case involves a preteen patient that has been very sick over the last month and has been hospitalized six times since May due to Sickle Cell disease and a current bile duct obstruction. Due to patient's sickle cell the patient has developed sickle cell retinopathy, which has led to retinal macular atrophy and amblyopia of both eyes. During the most recent admission to ACH, they were admitted with epigastric abdominal pain and due to the specific issue, the patient had to be med-flighted to another hospital for a biliary stent insertion where they remain inpatient. Once discharged, they will continue to have follow-up appointments. Family lives over two hours so the family has to travel back and forth for each admission and one of the caregivers stay with patient each time. This impacts this caregiver's ability to work. Patient's other caregiver was recently unemployed and is searching for job opportunities. Due to these multiple admissions and recent loss of income for both caregivers, the family has become behind in several bills including electric and rent. **Therefore, we are submitting for your consideration a request for \$392.18 for electricity and \$767.00 for rent. Total request: \$1,159.18 Case #1 was approved unanimously and granted the full amount of the request.**

Case #2: This case involves an eight-month-old patient who has been in the NICU birth due to a multiple area of issues including hydrocephalus and an undiagnosed interstitial lung disease that the team is still trying to diagnose. The patient has persistent pulmonary hypertension which made the patient spend time on the CVICU as well and still needed long term ventilation. Additionally, they have feeding difficulties and osteopenia and now have a shunt in place. Due to all of the respiratory issues, the patient will likely require several more months of treatment. The patient's caregiver is now the sole caregiver/financial provider who has other children at home and currently works. The caregiver's continued occasional presence at bedside is important as the patient is beginning to be aware of and interact with their environment. This current situation for the patient as well as the additional time demands on the caregiver to care for the children at home and maintain employment has been overwhelming and therefore, they have not been able to work their full-time shift consistently. This has resulted in the caregiver falling behind on their water bill. **Therefore, we are submitting for your consideration a request for \$608.27 towards their water bill. Total request: \$608.27 A question arose as to whether or not the water bill was for several months or if it included penalties for late payment. The requested amount was approved by all present, but may be reduced if ACH medico-legal team can persuade the water company to drop fees.**

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Case #3: This case involves a four-month-old patient who has been admitted to ACH since the beginning of May. The patient has a complex medical history including congenital absent left kidney, multiple congenital anomalies, airway clearance impairment, GT dependent, failure to thrive among others. The caregivers have employment, however due to the hospitalization and needs of the patient, they have been unable to work during the stay. At present, the caregivers have been informed that this hospital stay could be several months as the team needs to observe patient's growth and create a final respiratory treatment plan at that time. Family reported due to the current lack of work, they have become behind on paying several bills including their electricity, water, and gas.

Therefore, we are submitting for your consideration a request for \$113.76 for electricity, \$48.10 for gas and \$85.39 for the water bill. Total request: \$247.25 Case #3 was approved unanimously. The full request was granted.

Case #4: This case involves a newborn with a history of critical airway, status post procedures for her airway including supraglottoplasty and epiglottopexy. Patient is still requiring high flow nasal cannula support and g-tube feeding. The patient will also most likely require a tracheostomy prior to discharge. This will require a high level of care at home. In addition to the unexpected medical needs of the patient, one of the caregivers had an unexpected medical condition that left them unable to work. The other caregiver is trying to find work until the patient's discharge as they will need to be the home caregiver at that time. These situations have caused the family to fall behind on their rent this month. **Therefore, we are submitting for your consideration a request for two months' rent to help the family get back on their feet financially during the caregiver's job search.**

Total request: \$1752.00 Case #4 was approved unanimously. The full request was granted

Case # 5: This case involves a 3-month-old patient who has been hospitalized since birth, following a diagnosis of esophageal atresia. The patient's condition has required prolonged inpatient care, and they are expected to remain hospitalized for several more months. The patient's mother has been struggling to maintain consistent visitation due to having two other children at home to care for and unreliable transportation. The patient's mother sought assistance with repairs to her previous vehicle; however, the car has since become inoperable and beyond repair. She now faces the urgent need for a dependable, affordable vehicle to facilitate regular hospital visits and maintain care responsibilities at home. **Therefore, we are submitting for your consideration a request for a reliable vehicle so**

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mom will be able to be at bedside to make medical decisions and can be home to care for the patient's siblings. Total request: \$5,000.00 Case #5 is on hold pending an inquiry into whether this same family had been previously granted money for car expenses. When the details are determined, the request will be reduced by any amount that was previously paid. There was one dissenting vote on this particular case.

Case #6: This case involves a 2 year old patient who was admitted to the CVICU emergently due to severe anemia and decreased left ventricular function. The patient had to receive several blood transfusions where they developed a severe lung injury and had to be intubated for several days. Throughout their stay, the patient's mother has remained at bedside while their father has been caring for the patient's 4 siblings at home. Both parents work but dad's temporary work assignment ended early and mom also has had to remain at bedside for the last 2 weeks, leaving her unable to work. The family was able to pay half of their rent earlier this month but with both parents out of work, they have fallen behind on bills and the other half of the rent is now past due. The family is concerned that if they continue to fall behind on rent, they will be at risk of eviction. **Therefore, we are submitting for your consideration a request for the other half of the family's rent so they will not be at risk of eviction. Total request: \$425 Case #6 was approved unanimously and the full request was granted.**

Case #7: This case involves a 5 week old patient that has been hospitalized since birth. The patient was transferred to a higher level of care for evaluation of dusky abdomen and free peritoneal fluid on abdominal ultrasound which then resulted in a bowel obstruction. In addition to the bowel obstruction, the patient has also remained intubated since birth and has respiratory distress due to their prematurity. The patient's mother is employed but is currently not working and does not receive any maternity leave benefits. Mom is eager to get back to work but until then, she has been falling behind on several monthly expenses. **Therefore, we are submitting for your consideration a request for \$216.89 for electricity, \$80.25 for gas, \$151.33 for car payment, and \$210 for internet. Total request: 658.47 Case #7 was approved unanimously and the full request was granted.**

Five cases were approved for a total amount of \$4241.90. The remaining two cases are on hold pending further financial information.