

Dear Pastor

On June 8th, 2024, we are holding a benefit car show at Lutheran High School St. Charles for a very special young member of our LCMS community. Freyja Amber Bax, a baptized member of Zion Harvester, was born on February 25, 2023, with a very rare syndrome called Haddad's Syndrome. Haddad's is a combination of Hirschsprung's disease and CCHS (Congenital Central Hypoventilation Syndrome). As a result, Freyja will need 24-hour care and extensive medical care indefinitely. Freyja will be IV nutrition dependent, ventilator with trach dependent and reliant on an ostomy bag for the unforeseeable future. Freyja has been at Children's Hospital St. Louis since birth. We pray continually to God for miracles for Freyja. He in His grace has already bestowed many on her, and we thank Him!

On behalf of our committee and Lutherans for Life St. Charles, we are reaching out to our association churches for assistance in helping raise the funds needed for Freyja to come home once the adequate nursing staff she needs is secured.

Along with the car show we hope to have food, a bake sale, baskets to be raffled, vendors and the opportunity for monetary donations. As you can see there are many ways to volunteer time, talent, and treasure. We are asking you, Pastor, to please help us get the word out by sharing this within your congregation (Maybe your congregation has a LFL Church Contact Looking for an activity to plug into.) Please encourage other people to get involved as well as printing and posting the flyer provided. We hope to get many helping hands and participants in this June 8th Car Show at Lutheran High for Freyja all to The Glory of God.

We are seeking donations of bottled water (16.9 oz), pre-packaged baked goods and snack items to be sold at the car show. These items can be dropped off the morning of the car show or we can arrange the pickup of these items beforehand from your church. We are also in the process of procuring gift baskets for the raffle being held at the car show and perhaps someone at your church would like to donate a basket. We would also appreciate baked goods donations for the bake sale. Sponsors for the event are always appreciated as well as needed.

We would be honored to see you at the car show and share in our enjoyment of old and new hot rods for a wonderful cause.

We hope to get many helping hands and participants in this June 8th Car Show at Lutheran High to raise funds and support for Freyja and family, all to The Glory of God.

Freyja, "You were bought with a price" 1 Corinthians 6:20 We want to embrace your value to Lord Jesus and us.

Please feel free to reach out to the following people with any questions that you may have.

Christina Locke ecslocke@live.com 636-485-1631, Delores Desemone Volunteer Coordinator 636-447-3133 ddeemone@gmail.com and Shawnda Burnham Shawndab@hotmail.com

The Freyja Amber Box Benefit

At the Lutheran High School in St. Charles

All years,
makes &
model cars,
and
motorcycles
welcome.

Car Show

\$25 entry fee
for the first car
and \$20 for
each additional.
Pay at the event!

• SATURDAY, JUNE 8, 2024 •

(Rain date Saturday, June 15th)

The proceeds help offset medical bills, and medical equipment needed to provide Freyja with the best opportunity for a full life.

Check-in (registration for judging)

8:30 am - 10:30 am

Judging: 11:45 am - 1:30 pm

Awards: 2:15 pm

Haddad syndrome



Haddad syndrome (HS) is a very rare disease considered a form of neurocristopathy. It is characterized by a combination of congenital central hypoventilation syndrome (CCHS) and Hirschsprung's disease (HD).

About 15-20% of patients with CCHS are known also to have Hirschsprung's disease (aganglionic megacolon), an extremely rare combination (less than 1 in 1,000,000 live births) termed Haddad syndrome by some.

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**WE NEED VOLUNTEERS
AND SPONSORS!**

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OR VOLUNTEER!

