

## **NEXT STEPS:**

A GUIDE THROUGH DONATION





### **THANK YOU**

Whether the decision to donate was made by your loved one or by you on their behalf, we want to say thank you.

By saying yes to donation, your loved one will always be considered a donor and you a donor family. It is not the physical outcome of donation that defines this selfless act, but the time, patience, and support you have given us while we work to honor this tremendous gift.

By saying yes to donation you and your family are also providing hope to the growing number of recipients waiting for a life saving transplant. Your loved one has the ability to impact countless lives through their gift of donation and we will work hard to honor that gift and support your family.

Throughout this booklet we will discuss the next steps in the donation process, the phases of donation, and the continued support you will receive.

When we meet with you and your family it is likely after you have received devastating news about your loved one. It is at this time we will share with you the opportunity for donation and discuss those next steps. This conversation can be overwhelming and full of terms or phrases you have never heard of or used. Please reference this booklet as needed, jot down questions, or circle things you would like to review in more detail.

### **PHASE 1 = EVALUATION**

During this phase, Iowa Donor Network will work with the hospital staff to do several things: Review medical and social history we obtained from you by reviewing your loved one's medical records. Draw blood that is taken to a lab to test for communicable diseases and will help best determine who your loved one may be able to save. Continue to monitor labs. Work with our donation medical director to evaluate and optimize the gifts your loved one may be able to donate.

### PHASE 2 = CARE AND MANAGEMENT

During this phase your loved one will continue receiving medications to help support blood pressure and organ function. Everyone's care plan is different in this phase and dependent on which gifts your loved one can donate. For example, if your loved one's lungs have the potential to be donated, they may be proned or turned onto their stomach for a bit of time. This allows the lungs to rest in a different manner.

During this phase we may also complete scans and other imaging to best evaluate which organs your loved one will be able to donate.

### PHASE 3 = ALLOCATION AND ORGAN RECOVERY

During this phase we work with a national organization (UNOS) to receive a list of potential recipients. Prior to this phase, we do not know the length of the lists and/or if there is a potential recipient for your loved one's specific organ. We work diligently to go through each individual recipient and allow the transplant centers the time needed to make the best and safest decision.

Once allocation has been completed and the recipients your loved one will save have been located, we work to set a time for organ recovery in the operating room. This process can involve multiple institutions depending on where the transplant surgeons are located, as well as navigating the schedule of the hospital's operating room. Once a recovery time has been confirmed by all parties, we will update you and make plans for your loved one's honor walk, should you wish to have one.



## FUNERAL ARRANGEMENTS

The decision to donate organs and tissues will not impact funeral or burial arrangements. Families who support tissue donation and/or organ donation can have a viewing and open casket. While you are making your funeral arrangements, the funeral director will be updated by Iowa Donor Network's team of funeral directors about donation process and our involvement.

#### ORGAN DONATION

Organ donation has the potential to not only impact, but save the lives of those waiting on the recipient list. The organ recovery takes place after a recipient has been identified and a transplant surgeon is available for the surgery. During the organ recovery, your loved one will continue to be cared for by the medical team and treated with respect and dignity. A moment of silence will be held prior to the surgery and all those in attendance will hear a few words about your loved one.

The recovery of organs happens in one operating room, simultaneously. Once the recovery is complete, the surgeons will return to their respective hospitals to begin the transplant surgeries. Following the organ recovery, your loved one will be transported for tissue recovery, to the medical examiner's office, or to the funeral home/crematorium of your choosing.

An organ donor has the potential to save many lives through the gift of heart, lungs, liver, kidneys, intestines, and pancreas.

### **TISSUE DONATION**

Tissue donation has the potential to impact countless lives.

A tissue donor has the potential to impact 100's of lives through the gift of heart valves, skin tissue, bone and tendon tissue, arteries, veins, corneas, and both cartilage and vertebral tissue.

## BILLING & PAPERWORK

In order to move forward with donation, paperwork must be completed. This will include an authorization or disclosure form as well as a medical and social history on behalf of your loved one. The time of paperwork is also used to navigate hospital costs for donation as your family will to donation.





### WHAT IS THE DIFFERENCE BETWEEN AN AUTHORIZATION AND A DISCLOSURE FORM?

A disclosure form is a document that is read to you and your family that discloses your loved one's decision to be a donor, this happens when we meet with the family of someone who has registered themselves as an organ, tissue, and eye donor.

An authorization form is a document that is read to you and your family that gains authorization for lowa Donor Network to move forward with the process of organ donation. We complete this form with your family on behalf of your loved once as you are the decision maker.

There are two medical pathways to donation. One pathway is through brain death which is described below along with how brain death is declared. For individuals who are not brain dead, meaning they remain with reflexes, donation can happen after your family has made the decision to transition to comfort cares. A family advocate will discuss what donation steps are needed specific to each individual and the support we can provide through this process.

### BRAIN DEATH, A FORM OF DEATH DECLARATION

What does brain death mean? Your loved one has received the best possible care at the hospital and despite all the efforts, it has been determined through a series of tests that your loved one is brain dead.

Once two physicians have determined your loved one is showing signs of brain death, a clinical examination will take place at the bedside. A clinical examination will test for our most basic reflexes. These reflexes include response to light in our pupils, reaction to touch in several areas, cough reflex to suctioning, among others. In order for brain death examination to continue your loved one must have no response to these tested reflexes.

If this clinical exam shows no response, a confirmatory test must be completed. Most often this will be an apnea exam\* An apnea exam is a test to determine if your loved one has any respiratory drive. This test is performed with a physician present. The test begins with a blood sample to determine the amount of carbon monoxide in your loved ones' blood. Your loved one will be given oxygen but no machine assistance from the ventilator to breathe. Your loved one will be watched for breath movement for 8-10 minutes while the ventilator is off. At the end of the test, a second blood sample is drawn, and the ventilator is turned back on to full support.

The blood samples are compared and will tell us if your loved one's carbon monoxide level rose to a level that would force an individual with a respiratory drive to initiate a breath. It is after the apnea exam that brain death is confirmed, and a time of death is documented.

Brain death is a legal form of death and will include a time of death to be documented on the death certificate.

\*There can be clinical reasons an apnea cannot be completed, for those there are alternative confirmatory exams that the medical team will discuss with you.

"We always encourage people to become a registered donor. Our son Garrett has impacted hundreds, if not thousands of lives through his gifts – both directly and indirectly. Knowing he lives on through others and that their quality of life is so much better because of his gifts brings us great joy."

TIFFINI BROCKWAY DONOR MOM

### **RESEARCH**

lowa Donor Network is dedicated to you and your loved one, which is why we have partnered with multiple organizations that are able to advance donation through education, research, and therapy. For those gifts we are not able to transplant to a recipient, there is often an opportunity to donate for research. Donation for research is another way to honor your loved one and the decision to help others through the gift of organ, tissue, and eye donation.

While we complete paperwork, we will review with you the gifts eligible for research, education, and therapy. Once donation is complete, we will also be able to update you on how your loved one was able to impact countless individuals through their gift.

It is through the tremendous gift of research that we are able to serve future recipients and impact many more lives. Research is vital to medicine and as the list of those needing a life-saving transplant continues to grow, it is imperative we continue to learn how to advance our processes and find new ways to improve the lives of recipients and their families.

In the next couple of pages we will talk about how to continue your loved one's legacy, how to share their donation story, and how lowa Donor Network will continue to support you and your family in the weeks, months, and years ahead.

### **CELEBRATION OF LIFE, MEMORIAL SERVICES, AND FUNERALS**

How can I continue to share my loved one's donation story? Some families choose to include donation in their obituary. This is a way for you to highlight the incredible decision your family made by supporting organ, eye, and tissue donation and continue to honor your loved one as a hero. If you are not sure how to include this information, below are some examples of phrases:



(Your loved one's name) gave the gift of life through organ, eye, and tissue donation.



(Your loved one's name) will be deeply missed but will continue spreading love and joy as an organ donor to many.



(Your loved one's name) continues to give in death as they did in life by saving lives through organ, tissue, and eye donation.



(Your loved one's name) was a firm believer in helping when able and did so by being an organ donor.



In lieu of flowers,
we encourage
family and friends
to contribute to
the lowa Donor
Network in honor
of (your loved
one's) donation
of life.

Are there opportunities for donation to be shared at memorial or funeral services? Yes, for so many families sharing the decision to donate brings light to their memorial services. We want to provide as much support as possible. We will send green Donate Life bracelets, a donor medallion, framed outcome information, and brochures on how to register to be a donor in your loved one's memory. We also have options to add your loved one to our virtual memorial wall on the lowa Donor Network website. If your family would like someone from lowa Donor Network to be present at your service, please let us know.

#### WHAT ABOUT SOCIAL MEDIA? SHOULD I SHARE ANY INFORMATION ABOUT DONATION ONLINE?

Social media can be a very useful tool in updating many without feeling you have to reach out to each individual person. We know this can be exhausting and utilizing Facebook or Instagram to communicate to many can be helpful. If you are not sure what to say, below are some examples:



It is with great sadness we share that (your loved one) will not survive injuries recently sustained. We are taking the next couple days to give the gift of life through organ and tissue donation. We will up-date everyone once a service is planned and, in the meantime, we ask that you share your memories of (your loved one) so that their story can be heard.

Sadly, we must share that (your loved one) has died. As a shock as this is to our family, we are comforted knowing they will be able to save lives through being an organ donor. Please consider register-ing to be an organ donor in (your loved one's) memory. It is through this final selfless act of generosity that (your loved one) will live on.

We have covered a large amount of information in just a few short pages. At the end of this booklet, there is a place for notes, to jot down questions as you think of them, or to begin keeping track of who to call next. As we work through the coming days, please know we are available on site at the hospital or by phone for any needs or support.

### **IOWA DONOR NETWORK AFTERCARE SUPPORT**

We have a dedicated team of individuals who offer support in the days, weeks, months, and years to come. You will receive update phone calls as well as a letter letting you know how your support of donation has made an impact on others. Once we have completed paperwork with you at the hospital, we will formally enroll you in our aftercare program. If at any point you would like to hear more (or less) from us please don't hesitate to let us know.

As you are just beginning your grief journey, this list may feel overwhelming. Please know these are all options and if you want to take your time before trying out a group or webinar, that is understandable. As we have shared, we are available 24/7 and if at anytime you would like more information about any of these events or opportunities, please don't hesitate.



We also offer an opportunity to join our private Facebook support page as well as follow our other social media accounts for updates on events and Iowa Donor Network involvement in the community.

During and after the donation process, Iowa Donor Network is available for support, questions, and more. Please know we are available 24/7 by phone. In the coming days you will learn more about the donation process and the aftercare support Iowa Donor Network offers. Between the information from the hospital, Iowa Donor Network, Funeral Home, and more, things can feel overwhelming. It is important to take your time, write things down, lean on your family and friends, and ask questions as they come up.

Although we have met under the darkest of circumstances, please know we are grateful for your support during our process. Please use this space to keep notes during your time at the hospital, keep track of hospital and Iowa Donor Network staff, and keep a list of questions for us.

NOTES:

# WHERE TO REACH US

1.800.831.4131

contact@iadn.org



### **MAIN OFFICE**

550 Madison Ave. North Liberty, IA 52317 319.665.3787

### **REGIONAL OFFICE**

320 Adventureland Dr. NW Altoona, IA 50009 515.727.7897



- fb.com/iowadonornetwork/
- @iowadonor
- @iowadonornetwork
- youtube.com/lowaDonorNetwork

IowaDonorNetwork.org