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OUR MISSION

To find a cure and improve the quality of life for those affected by cholangiocarcinoma (bile duct cancer).
PRESIDENT’S MESSAGE

As we reflect back on 2016, it has been a time of exponential growth for our organization and our cause:

Since 2006, CCF has raised over $4 million to fund research, academic fellowships and patient education services. Our overall budget has increased from $560,000 in 2014 to a projected $1 million+ in 2017.

- Our website, which began as a small discussion board with five participants, now receives 300,000 visits from around the world each year.
- In 2006, there were 4-6 clinical trials available for patients. As of this writing, there are over 160 cholangiocarcinoma (CCA) trials available.
- When we started on this journey, there were few labs in the nation that was focused on CCA. By funding young, exceptional researchers willing to take a serious look at our rare cancer, there are now many more.
- The CholangioConnect Mentoring program was conceptualized in 2016 and launched in 2017 and we currently have over 25 patients and caregivers available to talk one on one with newly diagnosed individuals.
- The International Cholangiocarcinoma Research Network (ICRN) which started recruiting in 2016, now consists of 30 institutional members from around the world, all of which are collaborating together to support academic and industry research which will accelerate scientific discovery for CCA.
- Nearly 900 patients and caregivers have created personal profiles to date in our Patient Registry.
- Our 4th Annual Conference in February 2017 welcomed attendees from 16 countries, 31 states, and 76 major medical institutions.

We continue to pursue and embrace partnerships and collaboration with any medical professionals interested in improving treatment options and finding a cure for patients with cholangiocarcinoma globally. We continue to expand the depth and breadth of educational services we offer to patients and caregivers in the US and beyond. We continue to be leaders in patient advocacy and engagement, supporting public awareness, and striving to bring the word “cholangiocarcinoma” into the common vernacular.

We would not have been able to accomplish all of these efforts without our many volunteers and generous donors. We are grateful for your support as we continue to put the puzzle pieces together allowing us to see the bigger picture of this disease which will one day allow us to offer prevention, early diagnosis, and a cure. We look forward to continuing to work with you - thank you!

Stacie Lindsey

Stacie Lindsey President, The Cholangiocarcinoma Foundation
BOARD OF DIRECTORS

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Board Member
Warwick, RI

Dawn Duchene Lyon
Vice President
Trumbull, CT

Lawrence Goodfield
Treasurer
New York, NY

Stacie Lindsey
President
Herriman, UT

Jason Scott, PhD
Board Member
Los Altos, CA

Sean Turbeville, PhD
Board Member
San Francisco, CA
# Medical Advisory Boards

## Medical Advisory Board

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ghassan K. Abou-Alfa, MD</td>
<td>Chair</td>
</tr>
<tr>
<td>Juan Valle, MB ChB MSc FRCP</td>
<td>Vice Chair</td>
</tr>
<tr>
<td>T. Peter Kingham, MD</td>
<td></td>
</tr>
<tr>
<td>Lewis Roberts, MB, ChB, PhD</td>
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</tbody>
</table>

## Clinical Science Advisory Board

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
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<tbody>
<tr>
<td>Alan P. Venook, MD</td>
<td>Chair</td>
</tr>
<tr>
<td>Milind Javle, MD</td>
<td>Vice Chair</td>
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<tr>
<td>Mitesh J. Borad, MD</td>
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<tr>
<td>Daniel Catenacci, MD</td>
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<tr>
<td>Anthony B. El-Khoueiry, MD</td>
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<tr>
<td>Cristina Ferrone, MD</td>
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<tr>
<td>Renuka Iyer, MD</td>
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<tr>
<td>R. Kate (Katie) Kelley, MD</td>
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<td>Andrew X. Zhu, MD, PhD</td>
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## Basic Science Advisory Board

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Nabeel Bardeesy, PhD</td>
<td>Chair</td>
</tr>
<tr>
<td>Ben Stanger, MD, PhD</td>
<td>Vice Chair</td>
</tr>
<tr>
<td>Wolfram Goessling, MD</td>
<td></td>
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<tr>
<td>Aram Hezel, MD</td>
<td></td>
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<tr>
<td>Matthew Vander Heiden, MD, PhD</td>
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</table>

## General Science Advisory Board

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Steven Alberts, MD</td>
<td></td>
</tr>
<tr>
<td>Oliver Bathe, MD, FRCS(C)</td>
<td></td>
</tr>
<tr>
<td>William C. Chapman, MD, FACS</td>
<td></td>
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<tr>
<td>Michael Choti, MD, MBA</td>
<td></td>
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<tr>
<td>Laura Dawson, MD</td>
<td></td>
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<tr>
<td>Yuman Fong, MD</td>
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<tr>
<td>T. Clark Gamblin, MD, MS</td>
<td></td>
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<tr>
<td>Laura Williams Goff, MD</td>
<td></td>
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<tr>
<td>Gregory Gores, MD</td>
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<tr>
<td>Daniel G. Haller, MD, FACP, FRCP</td>
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<tr>
<td>Tomoaki Kato, MD</td>
<td></td>
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<tr>
<td>Richard Kim, MD</td>
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<td>Robin D. Kim, MD</td>
<td></td>
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<tr>
<td>Jennifer Knox, MD, MSc, FRCPC</td>
<td></td>
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<tr>
<td>Heinz-Josef Lenz, MD, FAC</td>
<td></td>
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<tr>
<td>Robert C. G. Martin II, MD, PhD</td>
<td></td>
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<tr>
<td>Rebecca A. Miksad, MD, MPH</td>
<td></td>
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<tr>
<td>Bruce D. Minsky, MD</td>
<td></td>
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<tr>
<td>Tushar Patel, MB, ChB</td>
<td></td>
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<tr>
<td>Timothy Pawlik, MD, MPH, PhD</td>
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<tr>
<td>Myron E. Schwartz, MD</td>
<td></td>
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<tr>
<td>Robert R. Selby, MD</td>
<td></td>
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<tr>
<td>Weijing Sun, MD</td>
<td></td>
</tr>
<tr>
<td>Jeffrey C. Weinreb, MD, FACR, FISMVR</td>
<td></td>
</tr>
</tbody>
</table>
NURSING ADVISORY BOARD

Susan Acquisto, DNP, RN, NEA-BC  
Chair
Elizabeth Bradley, Dietician
Lorraine Drapek FNP-BC, AOCNP
Karen Driskill, RN, CHPN
Renuka Iyer, MD  
Medical Advisor
Heidi Lowitzer, RN, CCRN
Lynne McCallum, Clinical Nurse Specialist, HPB & NET
Kaitlyn R. Musto, PA-C, MSPAS
Natasha Pinheiro, MSN, CNS, OCN, AGPCNP-BC, AOCNS
Michele Pratt, RN, MSN, FNP-C
Lauren Rosati
Marion Schwartz
Jacqueline Weatherly, MPAS, PA-C

Formed in 2014, the Nursing Advisory Board is a group of nursing professionals practicing in cancer research centers throughout the US and UK with expertise in care of patients with cholangiocarcinoma. Their goal is to advance the scientific knowledge of the symptom experience and quality of life of patients with cholangiocarcinoma. This is being accomplished by the development and publication of Clinical Nursing Practice Guidelines (CNPG’s):

- Care of the patient with external biliary drains and internal bile duct stents
- Care of the patient preparing to participate in a clinical trial and radiation therapy
- Care of the patient undergoing chemotherapy/management
- Care of the patient with intractable nausea and vomiting
- Care of the patient pre and post-transplant surgery
- Care of the patient on palliative care

Additional standards will be developed, however this list was established and prioritized by the group to begin this important contribution to nursing knowledge for the care of patients with cholangiocarcinoma.
**Fiscal Year 2016**

<table>
<thead>
<tr>
<th>Net Assets, Beginning of Year</th>
<th>$343,988</th>
</tr>
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<tbody>
<tr>
<td><strong>Revenues and Support</strong></td>
<td></td>
</tr>
<tr>
<td>Contributions</td>
<td>834,457</td>
</tr>
<tr>
<td>Grants Returned</td>
<td>60,000</td>
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<tr>
<td>In-Kind Contributions</td>
<td>8,356</td>
</tr>
<tr>
<td>Other Income</td>
<td>5,665</td>
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<tr>
<td>Interest Income</td>
<td>98</td>
</tr>
<tr>
<td>Investment Income</td>
<td>19</td>
</tr>
<tr>
<td>Loss on disposal of property and equipment</td>
<td>-692</td>
</tr>
<tr>
<td>Total Revenues and Support</td>
<td>$907,903</td>
</tr>
<tr>
<td><strong>Expenses</strong></td>
<td></td>
</tr>
<tr>
<td>Program Services</td>
<td>714,772</td>
</tr>
<tr>
<td>Management and General</td>
<td>119,291</td>
</tr>
<tr>
<td>Fundraising</td>
<td>89,822</td>
</tr>
<tr>
<td>Total Expenses</td>
<td>$923,885</td>
</tr>
<tr>
<td><strong>Net Assets, End of Year</strong></td>
<td>$328,006</td>
</tr>
</tbody>
</table>
In 2016, we raised nearly $908,000 for the fight against bile duct cancer, and 79% of those funds have gone directly to support our research, advocacy and education for our patients.
In 2015, the Cholangiocarcinoma Foundation launched the Research Fellowship Program to inspire innovative, quality research that will directly impact the study of cholangiocarcinoma or its treatment. In 2016, four grants were awarded to outstanding scientists throughout the country to gain insights and achieve significant milestones into the research of cholangiocarcinoma. We are proud to honor and support these remarkable scientists as they carry on the legacies of those for whom the grants are named:

2016 Innovation Award
*Contribution of Hepatic Stellate Cells to Intrahepatic Cholangiocarcinoma*
Amount: $50,000
Researcher: Silvia Affo, Columbia University

2016 Andrea Marie Fuquay Memorial Research Fellowship
*2-HG as a Biomarker in Patients with IDH-mutant Intrahepatic Cholangiocarcinoma*
Amount: $50,000
Researcher: Lipika Goyal, Massachusetts General Hospital

2016 Andrea Scott Memorial Research Fellowship
*A Hippo and Fibroblast Growth Factor Receptor Autocrine Pathway in Cholangiocarcinoma*
Amount: $45,000
Researcher: Sumera Rizvi, Mayo Clinic

2016 Christopher J. Wilke Memorial Research Fellowship
*Metabolic Reprogramming by IDH Mutation in Cholangiocarcinoma*
Amount: $50,000
Researcher: Lei Shi, Massachusetts General Hospital
2016 COLLABORATIVE RESEARCH GRANTS

International Cholangiocarcinoma Research Network (ICRN) Biorepository

Term and Amount: 2017: $71,100
2016: $30,798
2014: $25,000
2013: $41,607
2012: $40,000

Purpose: To develop a network of collaborating institutions pooling information for studies of the risks and outcomes of cholangiocarcinoma

The ICRN is a global collaboration of research groups from renowned institutions that are working in concert to improve knowledge about cholangiocarcinoma etiology, prevention, early detection, treatment, and prognosis. The network is comprised of highly talented individuals from a spectrum of disciplines, perspectives, and research methods who share the passion to make significant scientific advances that improve outcomes for patients with cholangiocarcinoma.

Genome Wide Association Studies (GWAS) - A Program of the International Cholangiocarcinoma Research Network

Term and Amount: 2013-2017: $296,000

Researcher: Lewis Roberts, MD Mayo Clinic, Rochester, MN

Aim: A genome-wide association study is an approach that involves rapidly scanning markers across the complete sets of DNA, or genomes, of many people to find genetic variations associated with a particular disease. Once new genetic associations are identified, researchers can use the information to develop better strategies to detect, treat, and prevent the disease. Such studies are particularly useful in finding genetic variations that contribute to common, complex diseases, such as asthma, cancer, diabetes, heart disease and mental illnesses.

Purpose: To accelerate research through the power of combining large amounts of data about genetic variations

Goals: To advance understanding of factors that influence health and disease by helping scientists uncover associations between individuals and disorders that are passed from one generation to the next.

To determine an individual’s risk of developing a particular disorder.

To help prioritize genes or genomic regions for further investigation.

Second-Line Chemotherapy in Advanced Biliary Tract Cancers: A Retrospective, Multicenter Analysis of Outcomes

Term and Amount: 2015-2016: $38,825

Researchers & Collaborating Institutions:
R. Kate (Katie) Kelley, M.D. - UCSF-Helen Diller Family Comprehensive Cancer Center
Maeve Lowery, M.D. - Memorial Sloan Kettering Cancer Center
Laura Williams Goff, M.D. - Vanderbilt-Ingram Cancer Center

Goals: To study outcomes for cholangiocarcinoma patients who did not respond to standard regimen of gemcitabine plus cisplatin

To design future chemotherapy trials for cholangiocarcinoma at multiple institutions
The International Cholangiocarcinoma Research Network (ICRN) concept was introduced by members of the CCF’s Medical, Clinical Science, and Basic Science Advisory Boards during the Cholangiocarcinoma Foundation Annual Meeting in Salt Lake City, Utah in February 2015.

The ICRN is a global collaboration of research groups from renowned institutions that are working in concert to improve knowledge about cholangiocarcinoma etiology, prevention, early detection, treatment and prognosis. The network is comprised of highly talented individuals from a spectrum of disciplines, perspectives, and research methods who share the passion to make significant scientific advances that improve outcomes for patients with cholangiocarcinoma.

The goal of ICRN is to accelerate the clinical translation of scientific discoveries to impact the lives of patients with cholangiocarcinoma.

ICRN Steering Committee

- Milind Javle, MD
  Chair
- Mitesh Borad, MD
  Co-Chair
- Ghassan Abou-Alfa, MD
- Anthony El-Khoueiry, MD
- Renuka Iyer, MD
- Katie Kelley, MD
- Lewis Roberts, MB, ChB, PhD
- Juan Valle, MB, ChB, MSc, FRCP
- Andrew Zhu, MD
Our discussion group is an online resource for information, emotional support and mentoring for patients, friends, caregivers and loved ones.

**Moderated and uncensored.**

4000+ Registered Users

14,000+ Topics

100,000+ Posts
This annual program seeks to develop sustainable participation of the medical and research communities in the field of cholangiocarcinoma by providing a forum to:

- Increase the knowledge of attendees about key issues central to the prevention, diagnosis, treatment, and cure for cholangiocarcinoma
- Present a diversity of perspectives focused on clinical, basic, and translational research
- Stimulate multi-disciplinary, cross-institutional collaborations
- Foster dialogue and inspire innovation

Further, because patients living with cholangiocarcinoma have a direct stake in their own medical care and are in a unique position to provide input, in 2016 CCF expanded its Annual Conference to include programming that addresses questions and concerns that are important to patients and their families. Patients and caregivers—having experienced the disease firsthand—were be invited to learn about cholangiocarcinoma, share their personal experiences, and contribute to future efforts to further cholangiocarcinoma research.
WEBSITE 2016 IN REVIEW

By the numbers

293,353 visits
977,767 page views
167,810 unique visitors

Our Reach

USA = 65.21%
UK = 8.56%
Canada = 5.54%
India = 3.04%
Australia = 2.88%
SOCIAL MEDIA

By the numbers

10,000 Facebook Likes
1,300 Twitter Followers
300 LinkedIn Followers
1,050 Instagram Followers
**Website Traffic Sources:**

- **45.9%** Organic search
- **23.5%** Referrals from other sites
- **13.9%** Direct Traffic
- **11.7%** Google AdWords
- **3.7%** Social Media
- **1.3%** Other
Every effort is made to be accurate. We regret any errors or omissions. Please contact our Director of Development, Kathi Wagner at kathi.wagner@cholangiocarcinoma.org with any corrections.
SUPPORTERS ($100-$249)

Mr. Ken Gamble
Mr. Paul Gamig
Mr. Larry Garman
Mr. and Mrs. Roger Garza
Ms. Mary Gaul
Mr. Mark Gearhart
Ms. Emily Gencarelli
Mr. Joseph Gencarelli
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Mr. and Mrs. Cliff and
Mary Gerbers
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Mr. Scott and Brandon
Gibbons
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Mr. Derrick Hamn
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Mr. and Mrs. Mark Hollister
Rick and Cheryl Holm
Susan Howard
Jeannie Hooker
Mr. Donald Horne
Terri Horner
Ms. Jackie Hornstein
Mr. Scott Hornstein
Stephen and Victoria Hsin
Ms. Carol Howard Leasure
Ms. Nancy Hsu
Mr. Peter Hughes
Mr. and Mrs. Victor Hugo
Mr. Douglas Hulvey
Mr. Kevin Hunter
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Ms. E Klein
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Joceline Leslie
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Manning LLP
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Foundation/Meredith Charitable Contributions Program
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Mr. Jack Metzger
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Ms. Catharine Miller
Ms. Joanne Miller
Ms. Sabine Miller
Ms. Jeanne Milligan
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Kevin and Ann Mitchell
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Mr. Jim Mooney
Mr. Patrick Moore
Ms. Meredith Mooney-Levin
Ms. Deborah Moore
Colleen Moore Forouzi
Mr. Kevin Morin
Garrett and Catherine Mosher
Mr. Sean Mosher
Mr. Michael Mosso
Mr. Patrick Mullen
Ms. Sharron Munro
Ms. Beth Murphy
Mr. John Murphy
Mr. Ryan Murphy
Ms. Karen Myers
George and Holly Mykulak
Mr. Rince Na Heireann
Rince Na Sonas

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Every effort is made to be accurate. We regret any errors or omissions. Please contact our Director of Development, Kathi Wagner at kathi.wagner@cholangiocarcinoma.org with any corrections.
PARTNERS ($250-$499)

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Agilent Technologies, Inc.
Agios Pharmaceuticals
AmazonSmile Foundation
Mr. Devon Anderson
Dr. Samuel Antwi
Ms. Joanna Apolinsky
Keith and Kelli Augenthaler
Patrick and Alejandra Banfield
Mrs. Kami Banks Kane
Banner MD Anderson
Mr. Edward Barlow
Ms. Wilma Baskinger
Battelle Always Giving
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Becton Dickinson Matching Gifts
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Berkadia Commercial Mortgage LLC
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Ms. Mary Pat Daniels
Dr. Alfar Dar
Deere and Co.
Diamond Title Company

Mr. David Dickey
Ms. Donna Drosner
Mrs. Angela Dufresne
Katherine Eastment
Emory Liver and Pancreas Center Winship Cancer Institute
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Malcolm Ewen
Ms. Mary Ewing
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Mr. Mark Goldshein
Ms. Erica Goode
William and Helen Gordon
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Ms. Cynthia Green
Ms. Jennifer Guynn
John and Marie Halpin
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Mr. Warren Hausman
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Highland Builders
Mr. Seth Hinkley
Todd, Shannon, Austyn and Abigail Holderfield
Vandy Howell
Ms. Alison Hudspeth
Ms. Kathleen Hunt
IMES Group, LLC
Mr. Kevin Kelly
Mr. Mahmudul Khan
Ms. Susanne LaFrankie-Principato
Kelly Lang and Larry Ayer
Mike and Caren Lara
Mr. Lonnie Lawson
Mr. Randy Lee
Mrs. W. Koi Lee

Mrs. Lucinda Legters
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