INTEREST GROUP 1: “CAMR”
COALITION FOR THE ADVANCEMENT OF MEDICAL RESEARCH

CAMR is an organization dedicated to advancing medical research in general, and stem cell research in particular, CAMR is a coalition of many different organizations that lobbies congress, and which organizes polls and data collection to gauge public opinion on issues in medical research. You are asked to read five short editorials produced by CAMR: (1) a set of “talking points” on stem cell research, (2) CAMR president Sean Tipton’s statement on the anniversary of the passage of H.R. 810 in the House, (3) a press release from CAMR coincident with Tipton’s statement, (4) a report of results from a poll measuring public support for stem cell research, and (5) a press release urging passage of H.R. 810. (This sounds like quite a lot, but some of these are only a page long.)

Your task is to prepare a brief statement to explain and justify CAMR’s view on stem cell research and on H.R. 810. You may frame your remarks as a presentation to the Senate to explain and justify CAMR’s position on this issue.

Here is the statement about the organization, taken from the CAMR website:
[http://demo.democracydata.com/capconnect71/camr/about_us.aspx] on May 27 2006:

The Coalition for the Advancement of Medical Research was formed in 2001 to ensure that the voices of patients, scientists, and physicians were heard in the debate over stem cell research and the future of regenerative medicine. The Coalition currently has a broad membership base of patient groups, universities, foundations and scientific societies unified in support of the following mission:

**Protecting and expanding opportunities for federal funding of biomedical research involving human embryonic stem cells**

**Why?** Embryonic stem cells show tremendous promise, federal funding of the research protects the public interest, and the majority of Americans support stem cell research.

Learn more about why CAMR supports funding of embryonic stem cell research

**Ensuring that somatic cell nuclear transfer (SCNT), also known as therapeutic cloning, remains a legal and viable form of scientific research, and opposing any effort that would allow reproductive cloning**

**Why?** Nearly 100 million Americans suffer from cancer, Alzheimer’s, diabetes, Parkinson’s, spinal cord injuries, heart disease, ALS, and other devastating conditions for which treatments must still be found. SCNT could hold the key to ending these patients’ suffering.
CAMR READING 1: CAMR Talking Points on Stem Cell Research


The Promise of Embryonic Stem Cells

Embryonic Stem Cells Have Great Potential

*The suffering of millions could end*

- These cells could be the “missing link” needed to cure some of the world’s most deadly diseases.
- Scientists already have shown they can direct the development of human embryonic cells into insulin-producing cells that might help cure juvenile diabetes.
- Up to 100 million Americans may benefit from this research.
- Embryonic stem cells offer more promise than adult stem cells.
- Most scientists believe and studies show that embryonic stem cells will likely be more effective in curing diseases because they can grow and differentiate into any of the body’s cells and tissues and thus into different organs.
- CAMR supports research involving both adult and embryonic stem cells.

Excess Fertilized Eggs Are Available For Research

*A majority of couples want to help save lives*

- Stem cells come from excess fertilized eggs stored in freezers at in vitro fertility (IVF) clinics.
- There are tens of thousands of these fertilized eggs available for research.
- Nearly half of infertile couples say they would like to see some good come from their excess eggs.

Federal Funding of the Research Protects the Public Interest

*Private funding means research without federal oversight*

- Without federal funding, the nation’s top academic researchers at universities, medical schools and teaching hospitals cannot join in the search for cures, which means much slower progress.
- Tax dollars keep the “public” in public interest. This research should not be confined to the for-profit, commercial sector.
- The government should be providing oversight of the work and ensuring that the research complies with ethical guidelines.
State Legislative Initiatives
State governments are promoting safe-havens for stem cell and therapeutic cloning research

- CAMR supports state efforts to create safe-havens for critical medical research such as stem cells and therapeutic cloning, but it is no substitute for a supportive federal policy.
- State legislation that is pro-stem cell and therapeutic cloning research helps attract top scientists/researchers to pursue this field of study and increases research activity.
- Increased research activity helps bring us closer to scientific advances that could lead to cures.
- State legislation that encourages IVF clinics to inform patients of their option to donate excess fertilized eggs for research helps increase the supply of material available for research. This in turn helps increase the genetic diversity of new stem cell lines that could be developed.
- State governments that pass anti-stem cell and therapeutic cloning legislation, such as Iowa, force researchers to flee to states like California and New Jersey, which provide funding and positive research environments.
- Broadly-worded state bans on all human cloning will only stop important research and possible cures.

Public Opinion Strongly Favors Embryonic Stem Cell Research

The majority of Americans (regardless of religious or political affiliation) support embryonic stem cell research

- The American people want embryonic stem cell research to move forward.
- Members of Congress from both sides of the political aisle support the research. In May 2005, the House of Representatives passed HR 810, the Stem Cell Research Enhancement Act. The bill is currently pending in the Senate.
- Independent opinion surveys over the last three years consistently show strong public support for embryonic stem cell research (USA Today, Gallup, Pew Research Center, ABC News, CAMR, and others).
- There is surprisingly strong backing among fundamentalist Christians, Catholics and abortion opponents.
- Hundreds of newspapers throughout the country have editorialized in favor of the research.

Updated August 2005
STATEMENT TO THE MEDIA: 24 May, 2006
The following statement may be attributed to Sean Tipton, president, Coalition for the Advancement of Medical Research:

"Today is the one-year anniversary of House passage of the Stem Cell Research Enhancement Act (H.R. 810), and still, there has been no action in the Senate. Many things have happened in the past year, since the House passed the Stem Cell Research Enhancement Act:

- 1,000 bills were introduced;
- 465 of them passed in the Senate; and
- 124 bills were presented to the President of the United States.

"However, while the Senate was considering those 1,000 bills, passing 465 of them, and sending 124 to the White House:

- 1.4 million Americans were diagnosed with cancer;
- 60,000 Americans were diagnosed with Parkinson’s;
- 11,000 Americans suffered spinal cord injuries; and
- 1.5 million adults were diagnosed with diabetes.

"And that’s just the tip of the iceberg. Many millions more already-diagnosed Americans continued to suffer from cancer, heart disease, Alzheimer’s, Parkinson’s, spinal cord injuries, and other debilitating diseases and disorders that scientists and the medical community believe can be better treated or cured through advances with embryonic stem cell research.

"In fact, earlier this month, the Senate spent time debating medical malpractice and other related legislation in a week they dubbed ‘Health Week.’ But, Senate Majority Leader Frist (R-TN) refused to schedule a vote on H.R. 810 – the one bill that holds the promise of a healthier America, thus reducing the cost of healthcare for Americans.

"Perhaps its time to remind Senate Majority Leader Frist of his own words, spoken last July after H.R. 810 passed the House with strong bipartisan support, when he said, ‘I believe the President’s policy should be modified. We should expand federal funding ... The promise is powerful enough that I believe this research deserves our increased energy and focus. Embryonic stem cell research must be supported.’

"Senator Frist’s words gave hope to millions of Americans, as well as the science and medical communities around the world. However, on this one-year anniversary of H.R. 810 with no Senate action, those same millions who once hoped for better treatments and cures now feel duped and are angrier than ever before."
“On behalf of CAMR, its members, and stem cell research advocates everywhere, I want to remind Senator Frist that tens of millions of patients, their families, their caregivers, as well as doctors and scientists have been counting on him to bring the Stem Cell Research Enhancement Act to the Senate for a vote. As Senate Majority Leader, he is in a unique and pivotal position to have the Senate act on H.R. 810, and we have been waiting for a year for him to do so.

“As it does with other kinds of promising technological and medical research, CAMR believes the federal government must fund human embryonic stem cell research. CAMR calls on the Senate to vote for H.R. 810 with no amendments and no alternatives. We believe this bill will pass, but if it is not scheduled for a vote, we not only risk the lives and well-being of millions of Americans and their families, we also risk losing America’s leadership position in the fields of science and medicine.”
ON ONE-YEAR ANNIVERSARY OF SENATE INACTION ON H.R. 810,
CAMR GIVES PATIENTS A VOICE ON CAPITOL HILL

- Derick Lindsey, Jackie Christensen, Lisa Clare and Michelle Mundt share "a year in the life" waiting for better treatments and cures through embryonic stem cell research -

WASHINGTON, D.C., May 24, 2006 – To commemorate the one-year anniversary of House passage of the Stem Cell Research Enhancement Act (H.R. 810), the Coalition for the Advancement of Medical Research (CAMR) hosted an event on Capitol Hill today to give patients and their families an opportunity to talk about their experiences over the past year – a year during which the Senate did not act on H.R. 810, despite promises from Senate Majority Leader Frist that the legislation would see swift action in the Senate.

"According to recent research, nearly three-quarters of Americans support stem cell research and want the Senate to vote on the Stem Cell Research Enhancement Act," said CAMR president Sean Tipton. "It has been a year since the U.S. House of Representatives showed strong bipartisan support in passing H.R. 810 and it’s time for Senate Majority Leader Frist to schedule this for a Senate vote now."

At today’s event in Russell Park on Capitol Hill, Washington, D.C., mother Michelle Mundt said, “Last year, I had two important reasons to support the passage of the Stem Cell Research Enhancement Act -- my husband Tim and my 3-year old son Duncan, who both have Type 1 diabetes. This year, I have a third reason -- my 5-year old daughter Caitlin was diagnosed with Type 1 diabetes. Unfortunately, diabetes hasn't taken a year off while we waited for the Senate to act. Every year we delay in finding a cure for diabetes, our family will endure another 3,000 insulin injections and another 7,000 finger sticks. We can't afford to wait any longer. The Senate needs to act now to fulfill the promise that stem cell research holds for my family and millions of other families like ours."

Reading from a college application essay, Derick Lindsey said about his experience with Stage 4 non-Hodgkin’s lymphoma, “I became sick nearly all the time. I was sleeping all the time, puking and running high fever. A simple-minded person would have thought that nothing good could come from this. Shortly after starting chemo, my hair began to fall out very rapidly, and I had thoughts like, ‘no one will want to be friends with a bald kid,’ and ‘no one will want to go to prom with a bald kid.’ I had missed so much of my life being in a hospital, and once again, I had to continue my life going to the hospital every week and barely having time for school or friends for a year.”

Minneapolis resident Jackie Christensen suffers from Parkinson’s Disease. After having risky Deep Brain Stimulation surgery to try to keep her Parkinson’s symptoms at bay, she said that the surgery “will mask my symptoms for an unknown period of time, improving my quality of life, but it does nothing to slow the progression of the disease. It has not
been so beneficial to our finances: the expenses associated have already cost us about $8,000. We are extremely blessed to have good insurance, because there is no way we'd have been able to pay the $137,000 bill. Many others with Parkinson's are not so lucky. They may be ineligible for the surgery because of other health issues, or simply unable to afford it. If my disease can progress so much in a year and I can take the steps I must for the sake of my life and my family, then why can't Senator Frist take the action he promised almost a year ago and allow this bill to come to a vote?"

Lisa Clare, from Leesburg, VA spoke at the event about her daughter MacKenzie, a Girl Scout who was paralyzed in a car accident in 2005, "When my husband and I heard that our 10-year old daughter would never walk again we nearly fainted. However, we were blessed with hope. One of MacKenzie's doctors told us to get her exercising immediately... that we needed to keep her body healthy because embryonic stem cell research showed potential to repair the spinal cord. We have no doubt that someday MacKenzie will walk down the aisle with her Daddy on her wedding day, have children of her own, and be the veterinarian that she wants to be! Please Vote 'yes' on the Stem Cell Research Enhancement Act with no amendments and no alternatives. We consider this the only pro-research vote there is!"

Boston-area resident Chaz Southard was paralyzed from a neck fracture he sustained in August 2002. Unable to come to the event due to current health problems, Chaz, a quadriplegic, wrote in an email to CAMR president Sean Tipton, "This past year has been hell for me and for my family. Not many people know that a very common complication to paralysis is vulnerability to infection. The bacteria that have invaded my body this past year have limited medical options for treatment. Any cut or burn on my body can become life threatening within eight hours. I have been on intravenous antibiotics three times in the past year and on another antibiotic that costs $1,200 for a ten-day cycle of medication. Every day is full of pain and anxiety. My family has dedicated themselves to keeping me alive until there is a cure. Every night I go to bed praying that our leaders will one day stand behind the people who cannot stand for themselves. I ask you today to please vote into law the Stem Cell Research Enhancement Act as it is written so that I and millions of others who suffer from the scourge of paralysis may look to the future with hope."

"As it does with other kinds of promising technological and medical research, CAMR believes the federal government must fund human embryonic stem cell research," Tipton added. "CAMR calls on the Senate to vote for H.R. 810 with no amendments and no alternatives. We believe this bill will pass, but if it is not scheduled for a vote, we not only risk the lives and well-being of millions of Americans and their families, we also risk losing America's leadership position in the fields of science and medicine."
For Immediate Release: Wednesday, July 13, 2005

Coalition for the Advancement of Medical Research Says Passage of H.R. 810 Critical for Patients and Science

Alternative Means of Deriving Stem Cells from Embryos is Unproven And Could Delay Or Set Back Benefits of Research

WASHINGTON, July 13 — Senate passage of H.R. 810 would be the surest way to bring the humanitarian benefits of stem cell research to millions of Americans suffering from diseases such as Parkinson’s, Alzheimer’s, diabetes, cancer, heart disease and many other serious illnesses, a non-profit coalition of 95 patient groups, medical organizations, and academic medical centers said today.

Daniel Perry, President of the Coalition for the Advancement of Medical Research (CAMR), attended a press conference with actor Michael J. Fox, Senators Orrin Hatch, Arlen Specter, Tom Harkin, Ted Kennedy, Dianne Feinstein and Representatives Michael Castle and Diana DeGette, calling on the Senate to pass H.R. 810.

“Legislation suggested by some as alternatives to the House-passed bill only delays bringing hope to millions of Americans,” Perry said. “We need a national lifting of the cloud of politics that currently hangs over embryonic stem cell research. Senate passage of H.R. 810 would lift that cloud and ensure critical federally-funded research can continue.”

The legislation, passed 238-194 by the House of Representatives on May 24, would allow federally-supported scientists to study additional stem cell lines, expand research among America’s top academic researchers and accelerate the cure and treatment of diseases that affect up to 100 million Americans. H.R. 810 expands Federal research of additional stem cell lines from voluntarily donated in vitro fertilization (IVF) embryos.

Opponents of H.R. 810 are promoting alternative means of deriving stem cell lines from excess IVF embryos, but because the alternatives have yet to be proven they cannot be considered substitutes for embryonic stem cells.

“Why would you want to bet on these kind of things today at the expense of embryonic stem cell research, which we know works? The science behind these alternative methods is uncertain and this point, and none of the methods has proven successful thus far,” Perry said. “These approaches are a catch-all bag of speculation, unpublished science, wishful thinking and philosophical pretzel-bending.”
The Coalition for the Advancement of Medical Research (CAMR) is the nation's leading pro-cures coalition. It is comprised of nationally-recognized patient organizations, universities, scientific societies, and foundations advocating for the advancement of breakthrough research and technologies in regenerative medicine - including stem cell research and somatic cell nuclear transfer - in order to cure disease and alleviate suffering for individuals with life-threatening illnesses and disorders.
NEARLY THREE-QUARTERS OF AMERICA SUPPORTS EMBRYONIC STEM CELL RESEARCH

WASHINGTON, D.C.; May 16, 2006 – The Coalition for the Advancement of Medical Research (CAMR) announced today poll results revealing that nearly three-quarters of Americans support embryonic stem cell research and want the Senate to vote on federal funding for stem cell research.

When asked if they support embryonic stem cell research, seventy-two (72) percent of respondents favor it, up from sixty-eight (68) percent in 2005. Only twenty-four (24) percent opposed embryonic stem cell research, down from twenty-eight (28) percent a year ago.

When asked given what they know about stem cell research, should the Senate vote on H.R. 810, seventy (70) percent of those surveyed said “yes,” while only eighteen (18) percent said “no” and twelve (12) percent were unsure.

At an event on Capitol Hill today, CAMR representatives, as well as Senator Dianne Feinstein (D-CA), Senator Tom Harkin (D-IA), Senator Orrin Hatch (R-UT), Senator Edward Kennedy (D-MA), Senator Gordon Smith (R-OR) and Senator Arlen Specter (R-PA) called on Senate Majority Leader Bill Frist (R-TN) to schedule a vote on The Stem Cell Research Enhancement Act (H.R. 810).

“America is ready for the Senate to vote ‘yea’ on H.R. 810 and for the federal funding of embryonic stem cell research,” said Sean Tipton, president of CAMR. “Just as it does with other kinds of promising technological and medical research, the federal government must fund human embryonic stem cell research. Senate Majority Leader Frist needs to understand that if this bill does not get scheduled for a vote, we not only risk the lives and well-being of millions of Americans and their families, we also risk losing America’s leadership position in the fields of science and medicine,” added Tipton.

On May 24, 2005, the U.S. House of Representatives passed H.R. 810 -- The Stem Cell Research Enhancement Act -- with strong, bipartisan support. If this bill passes the Senate, this bill will override President Bush’s August 9, 2001 executive order limiting federal funding of embryonic stem cell research. Thousands of scientists, including 80 Nobel laureates, recognize that current federal restrictions on stem cell research seriously hamper research in the United States.
"We believe that this legislation will pass the Senate, just as it did in the House, with strong bipartisan support," added Tipton. "We call on Senator Frist to schedule a vote on this important legislation before the one-year anniversary of hours passage next week. If you are one of the millions waiting for a cure or new treatment, a year is too long to wait for action. We need a vote and we need it now."

The poll was conducted by the Opinion Research Corporation with a nationwide random sample of 1,000 people the week of May 5, 2006, and carries a margin of error of +/- two (3) percent. More information about the poll and its results can be found at http://www.camradvocacy.org/resources/POLL_5_2006.pdf.

(Poll questions and data can be found on the following pages.)
I'm going to read you a brief description of embryonic stem cell research, and then get your reaction. Embryonic stem cells are special cells that can develop into every type of cell in the human body. The stem cells are extracted from embryonic cells produced in fertility clinics and then frozen days after fertilization. If a couple decides that the fertilized eggs are no longer needed, they can choose to donate the embryos for research or the clinic will throw the embryos away. Scientists have had success in initial research with embryonic stem cells and believe that they can be developed into cures for diseases such as cancer, Parkinson's, heart disease, juvenile diabetes, and spinal cord injuries.

Having heard this description, do you strongly favor, somewhat favor, somewhat oppose, or strongly oppose medical research that uses stem cells from human embryos?
Question VI

I'm going to read you a brief description of embryonic [em bree AH nik] stem cell research, and then get your reaction. Embryonic stem cells are special cells that can develop into every type of cell in the human body. The stem cells are extracted from embryonic cells produced in fertility clinics and then frozen days after fertilization. If a couple decides that the fertilized eggs are no longer needed, they can choose to donate the embryos for research or the clinic will throw the embryos away. Scientists have had success in initial research with embryonic stem cells and believe that they can be developed into cures for diseases such as cancer, Parkinson's, heart disease, juvenile [Joo vuh ny ul] diabetes [dy uh BEE teez], and spinal cord injuries.

Having heard this description, do you strongly favor, somewhat favor, somewhat oppose, or strongly oppose medical research that uses stem cells from human embryos?

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Given what you know now about the research and the status of embryonic stem cell research legislation in Congress, do you think the leaders of the Senate should allow an up or down vote on the legislation, or should they not permit a vote on this legislation?

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<td>5</td>
<td>13</td>
<td>14</td>
<td>8</td>
<td>7</td>
<td>5</td>
<td>12</td>
<td>11</td>
<td>16</td>
<td>45</td>
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</tbody>
</table>

Proportions/Means: Columns Tested (5% risk level) - B/C - D/E/F/G/H/I - J/K/L/M - N/O - P/Q/R
Overlap formulae used. * small base

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Given what you know now about the research and the status of embryonic stem cell research legislation in Congress, do you think the leaders of the Senate should allow an up or down vote on the legislation, or should they not permit a vote on this legislation?

<table>
<thead>
<tr>
<th>Household Income</th>
<th>H.H. Size</th>
<th>Children In H.H.</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total (A)</td>
<td>(B)</td>
<td>(C)</td>
<td>(D)</td>
</tr>
<tr>
<td>LT (E)</td>
<td>LT $35K</td>
<td>H.H.</td>
<td>Incomple</td>
</tr>
<tr>
<td>$50K-75K</td>
<td>LT More</td>
<td>Size</td>
<td>Grad</td>
</tr>
<tr>
<td>More</td>
<td>H.H.</td>
<td>H.H. Size</td>
<td>Grad</td>
</tr>
<tr>
<td>Total (F)</td>
<td>(G)</td>
<td>(H)</td>
<td>(I)</td>
</tr>
<tr>
<td>LT (J)</td>
<td>LT</td>
<td>More</td>
<td>None Total</td>
</tr>
<tr>
<td>$35K-75K</td>
<td>LT</td>
<td>More H.H.</td>
<td>Under 12-</td>
</tr>
<tr>
<td>More</td>
<td>H.H.</td>
<td>H.H. Size</td>
<td>17</td>
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<tr>
<td>Total (K)</td>
<td>(L)</td>
<td>(M)</td>
<td>(N)</td>
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<tr>
<td>LT (O)</td>
<td>LT</td>
<td>None Total</td>
<td>Grad Grad</td>
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<tr>
<td>$75K</td>
<td>LT More</td>
<td>Under 12-</td>
<td>Grad Grad</td>
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<tr>
<td>More H.H.</td>
<td>H.H.</td>
<td>H.H. Size</td>
<td>Grad Grad</td>
</tr>
<tr>
<td>Total (P)</td>
<td>(Q)</td>
<td>(R)</td>
<td>(S)</td>
</tr>
</tbody>
</table>

Unweighted Total:
- Should allow vote (Net): 701
- Yes, should allow vote: 637
- Probably should allow vote: 64
- Not sure: 56
- Should not allow vote (Net): 183
- Probably should not allow vote: 38
- No, should not allow vote: 146
- Don't know: 60

Weighted Total:
- Should allow vote (Net): 701
- Yes, should allow vote: 637
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