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Alcor News Bulletin

Number 21: February 6th 2004

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First Words

As this issue goes out the times are somewhat interesting and the outlook a bit guarded, but, I think, quite hopeful overall. Tanya Jones [TJ] has written almost all of what follows; my editing is minor.--Mike Perry [MP]

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Two Pets Added to Patient Population

An unusually busy month, January saw two pets added to our patient population, both sudden deaths, which meant that both were straight-frozen. Each of the owners placed their pets on ice until they could make the arrangements for preservation, but no cryoprotection was possible in either case. [TJ]

An Almost-Case

We also had one emergency notification that a member had died. We got a call from the manager of a Jewish Community Center who observed a member's collapse during an evening performance. After calling 911, the manager called Alcor, having seen the medic alert tag our member was wearing.

Though the member's heartbeat and breathing had ceased, paramedics managed to revive him and transport him to a local hospital. Our member then recovered sufficiently to be sent home that night.

The community center manager had told us the name of the hospital where the member was to be taken, and we promptly got on the phone to the emergency room staff. After escalating our call to the Nursing Supervisor, we ran into trouble obtaining information over the phone, a direct result of the HIPAA regulations (<http://www.hhs.gov/ocr/hipaa/>) recently enacted to protect patient privacy. Apparently, no information can be given out over the phone at all, and our possession of anatomical donation forms and a contract to cryopreserve were not enough to gain us any information on the member.

When we were denied, with regret, by the Nursing Supervisor, I dove back into the member's paperwork to determine if we had next-of-kin information. When I saw the contact information was thirteen years old, I was skeptical, but tried calling the member's sister. The phone number indeed was valid, and the sister was able to contact the hospital on our behalf. She established that her brother was alive and recovering, which was good news.

We have now been introduced to the complications that HIPAA will cause. Our Medical Director, Dr. Jerry Lemler, will be looking into these regulations more thoroughly to determine what changes need to be made to our paperwork. You can expect a mailing from us when we have the details resolved, and we know how best to arrange our paperwork to ensure we can both give and gather necessary information in an emergency. [TJ]

Training Update

For those people waiting to attend the training class that had been scheduled for March, I have regretful news. This class is being postponed indefinitely, because we simply do not have time to prepare for it properly right now. Alcor has become involved in a high-priority, state-level legislative matter (more below) that is occupying much of our time and attention.

That this class is being postponed for now should not be interpreted as a lack of commitment to training. We are still firmly resolved to carry out regular training for members of our transport network, and will let you know when the classes are scheduled.

In the interest of observing a local transport training session, I traveled to Los Angeles to meet with members of the Southern California team. This session was intended to be a brainstorming session, as opposed to a practical meeting, which fit well with Alcor's need to update our members on recent Scottsdale activity. To a large degree, this meeting consisted of discussion about concerns that have accumulated over time; and it highlighted that there is still a lot of work that can be done to improve our remote

transport capability, including development of more thorough operating procedures.

Before the next Alcor HQ training class, we will be reworking the training materials and standard operating procedures, as well as the process whereby the requisite skills are taught. More hands-on practice, better testing, a modular approach to certification, and a significant number of SOP revisions are all needed. Several of the ACTs have offered to assist with development of training materials, and we'll be contacting you when it's time to reschedule the class. [TJ]

Cryonics Magazine Update

As I type this newsletter in early February, the current issue of _Cryonics_ is being put to bed. It should be in the mail to you next week, and we apologize for the extreme lateness of this publication. All subscriptions will be extended, and our CEO Joe Waynick has decided to increase the number of issues each year from four to six to try to make the magazine timelier. [TJ]

Update on Old Business

Some of you have asked for an update on a couple pieces of old business: the health of Dr. Lemler and the status of the Larry Johnson litigation.

On the first matter, we can state with great happiness that Dr. Jerry Lemler's cancer is in full remission, and he is recovering well from his extended bout of radiation treatments. Since resigning as Alcor's CEO, Dr. Lemler has accepted a position as Medical Director of the Southwest Behavioral Health Services, Rim Guidance Center Division, in Payson, Arizona. Dr. Lemler will be relocating soon. He intends to return to Scottsdale on the weekends, but is still quite happy to be involved and on-call as our Medical Director.

On the Larry Johnson litigation, I regret that we are still unable to provide an update beyond our assurance that we (and our attorney) are pursuing this matter. Once the legal issues have been conclusively resolved, we'll be able to discuss them openly. [TJ]

A Legislative Matter

I will now get to the main substance of this past month. A couple weeks ago, one of our attorneys contacted us about some rumors from the Capitol. He'd heard that cryonics-unfriendly legislation was about to be introduced to the House of Representatives, and he recommended that we look into this immediately. Since we're obviously not well-connected to the state legislature, he also recommended an experienced lobbyist to investigate on our behalf.

After some discussion among the Board members and executive team, we decided to move ahead with hiring this lobbyist, Mr. Barry Aarons. Aarons has more than thirty years' experience and seems to know just about everyone at the Capitol. He jumped on the issue, and immediately got us invited to a stakeholders' meeting where the new legislation was being considered.

At the meeting Joe Waynick, Barry Aarons, and I met with Congressman Bob Stump and others involved with the recent drafting of cryonics legislation. Also represented were: the Department of Health Services, Funeral Board, RTI Donor Services, and Science Care (the latter two being organizations that also accept anatomical donations in the state of Arizona.)

Aarons quickly reminded the audience that we were latecomers to the proceedings, which had quietly begun some months ago, in August or September, without Alcor being informed. He emphasized that, while we are not unconditionally opposed to regulation, it is crucial that any new legislation be properly crafted to protect our right to carry out cryopreservations and must not endanger our patients.

Congressman Stump failed to adequately explain why we were not earlier invited to the table, but indicated that the goal was to create oversight to prevent potential problems rather than specifically to regulate. Randy Bunker of the Funeral Board said that the intent was to prevent people from engaging in cryonics without proper procedures, citing the Prescott case of last year in which a man had been secretly storing his wife in dry ice for nearly six years.

When queried, the representatives from the Department of Health Services stated that there was no obvious public health need to require their oversight, and that health needs end at the moment of pronouncement as long as no risk of contagion exists. DHS personnel would very much like to ensure that this line of demarcation be maintained.

We were queried extensively on why the Funeral Board is an inappropriate organization to put in charge of cryonics. Those in attendance expected our reasons to be primarily philosophical, that we just didn't want to be overseen by the Funeral Board because of their essential end-of-life care. We were able to cite differences in procedures that make other supervision more appropriate, and we reminded them that our efforts are intended to extend the lives of our patients, despite the declaration of legal death that occurs. The members of the Funeral Board were familiar with the recent regulation of the Cryonics Institute as a cemetery, and we discussed the differences between the organizations that would make such a designation less applicable to Alcor. This part of the discussion seemed to have thrown enough doubt on the subject that their suggestion to change the name of the Funeral Board to something more accommodating was dropped.

They also asked about the neuro procedures we perform, since that is another way we differ from CI. That gave me an opportunity to expand on how neuro procedures currently provide a superior preservation, and provided a platform for

discussing some of the aspects of our research other than the simple application of cryopreservation protocols.

When their questioning had by appearances ended, I was able to ask why they seemed insistent on revoking our ability to use the Uniform Anatomical Gift Act to protect our donors. No one was able to give a clear response, but they indicated that the UAGA Revision Committee had been involved in previous meetings and that a distinction between our procedures and those of conventional donations was necessary. When asked why the UAGA was so important to us, I responded that it was our mechanism to protect the rights of the donor after pronouncement. Enforcement of that act includes provisions that the next-of-kin may not overturn any such donation without sufficient proof. Without its protection, we open ourselves to significant risk for being at the center of all-too-frequent family squabbles.

While there was some doubt in the beginning as to whether this bill would actually be introduced, we have since learned it definitely will be. Our actions are now shifting from prevention to active opposition.

Since the stakeholders' meeting, Joe Waynick, Barry Aarons, and I have met with our two district representatives and a few senators, soliciting their support in quashing the bill. So firmly in our corner was one representative that the first thing she said was that this regulation was unnecessary and hasty, and she opposes it. The other was a little more hesitant, but with a nursing background she actually understood most of the reasons why the Funeral Board is an inappropriate oversight organization. We have a meeting set up with the Mayor of Scottsdale next week, and will continue our efforts to gain support for our case.

Once the "intro set" is filed with the Clerk of the House, it will be formally considered a "bill" and given a reference number. An electronic copy will be placed on the Arizona State Legislature website. (We'll circulate that bill number once we have it.) Once that is done, the bill will first be read on the House floor at a very rapid rate (one of three required readings in this process). It will then be eligible for assignment to committee for review. The more committees it's assigned to, the better it is for us. At minimum, a proposed bill must go to the Rules Committee, where it is evaluated for constitutionality and proper form, but this one is likely to be handed to other committees too, since more money will be required for the Funeral Board if they are granted oversight.

Once committee assignments are complete, we'll begin meeting with all committee members and gathering supporters of MD and PhD caliber to testify on our behalf against the legislation. We need to ensure that there will be hearings on this bill. Our Arizona members will be encouraged to contact their senators and representatives to ask them to help kill the bill. We'll be drafting a letter for folks to send, once we have all the information needed to make that letter effective.

We'll also be talking to multiple other organizations that may be inadvertently affected, since the Funeral Board would

be assuming oversight responsibility for all organizations that store bodies or body parts (except for blood) for more than five years. We're hoping this will all serve to get this current bill stopped, and open the door for more appropriate oversight in the future, assuming of course, that we cannot avoid regulation completely.

We'll keep you posted on details as they develop. [TJ]

Alcor Central Meeting

Alcor's next general meeting will be held on Saturday, February 7, at 11am MST (10am PST, noon CST, 1pm EST). Alcor meetings are now held in the new conference room at the facility's location in Scottsdale. [MP]

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End of Alcor News bulletin #21 dated February 6th, 2004.
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