

Foundation for Thymic Cancer Research

Protective Clothing Initiative

Progress to Date

The Department of Textiles and Apparel of Cornell University, under the direction of Associate Professor Susan P. Ashdown, is working on the design of basic tops for radiation patients. It is our plan to create prototypes of the completed designs for testing at selected radiation centers. The test garments will have a special identifying label of the Foundation, which will be placed on the hem so as not to abrade the neck. The Avery Dennison Corporation is donating the labels.



Until the time when Foundation garments are available, we have been selecting off-the-rack items that meet some of our basic criteria for comfort. These include tank tops with a built-in bra and straps that are wide enough not to cut into the shoulders. In addition, the A. S. Tees Company has donated 22 dozen knit tank tops that are very soft and have a suitable neckline.

It is our goal to have the Foundation garments and suitable off-the-rack garments available for display at the Celebrity Luncheon and Auction, to be held at Resorts Casino Hotel on April 18, 2004. We hope that resulting publicity of the event may encourage manufacturers to work with us in the production of these garments.

We are also hoping to enlist the aid of a key fashion designer to utilize our basic criteria in a way that shows that radiation patients can be comfortable and fashionably dressed.

Design Considerations

We are faced with finding both a design and material that radiation patients can wear.

There are basically four types of patients:

(1) Radiation to the left of the neck



(2) Radiation to the right



(3) Bilateral radiation and neck surgery patients



(4) Radiation to the thorax upper chest



Material cannot touch or rub on the radiated area, and garments must be easy to put on and take off. For women, they sometimes have a hard time wearing under-garments because the straps cut into the neck, so they need material that is firm enough to wear without an under-garment and non-revealing, perhaps with built-in support, without an underwire.

For neck patients, the garment should be cut to avoid their side of the neck. For thorax patients, it should be low cut to avoid that area, and perhaps a closure front so it can be adjusted for even lower areas.

Some styles that seem to work better are shown here:



Basic light tops with low neckline and straps/shoulders away from the neck.

For patients with surgery/radiation on one side of the neck
Affected side of neck and shoulder is not touched



These tops, which could be the tops of a dress, have low neckline for patients with surgery/radiation to the thorax area. Buttons allow the top to be easily put on and taken off. The buttons also allow the patient to adjust the neckline lower as needed.

Mission of the Foundation

As stated in our application for tax-exempt status, our foundation has the following goals:

- To collect and share information regarding the treatment, prognosis, and causes of thymic-related cancers and carcinomas, and making this information available at no charge.
- To educate family physicians and oncologists to the nature of thymic-related cancers to improve diagnosis and treatments.
- To identify the various modes of treatment and to promote research into other modes.
- To help promote the development of support systems and a better understanding of the various forms of thymic-related cancers.
- To collect anecdotal patient histories that may help other patients.
- To develop a database of physicians, pathologists, and other medical personnel with experience in thymic-related cancers and carcinomas.
- To develop products (such as wearing apparel for radiation-sensitive skin) and services to ease the suffering of patients having radiation therapy to the head and neck area due to thymic-related cancers and carcinomas.

History of the Foundation

In early 2002, Barbara Neibauer was diagnosed with a rare form of cancer, Ectopic Thymic Tissue Carcinoma. We began searching the medical literature and consulting physicians to find out more about her condition only to discover that very little literature was available on thymic-related cancers in general. There were no organized support groups, some confusion about treatment protocols, and many physicians lacked basic knowledge regarding diagnosis and treatment.

Barbara had a nine-hour surgery, followed by radiation treatments. During the process, it became clear that the confusion over treatment protocols and the lack of available information could easily result in improper treatment. Through much diligence and research, including contact with specialists throughout the world, Barbara received excellent care and has all hopes of recovering.

We decided that other patients with thymic-related cancers should be spared the same efforts that we went through. To that end, we began the Foundation for Thymic Cancer Research, a tax-exempt 501(c)(3) organization dedicated to improving the quality of life of thymic cancer patients.

The Need for the Project

Barbara's radiation made it difficult for her to wear clothing, so we spent much effort trying to find clothing and medications to ease her suffering. There were some off-the-shelf products that she could wear but only after much trial-and-error, resulting in wasted expenditures. In most cases, however, we couldn't find tops that didn't abrade the radiation area, or were soft enough and label-free, so Barbara herself had to modify some of her shirts by cutting out sections of the neckline to make them comfortable enough to wear.

During the weeks of trying various cover-ups, and combinations of tops, her radiation sensitive skin became quite sore, making it even more difficult to locate suitable clothing.

Audience Served

Distribution of the shirts will be made nationwide through referrals from cancer centers, hospitals, radiologists, and social workers. Patients must have received neck or thorax radiation for thyroid or thymic-related cancers.

Goals, Objectives, and Action Plan

The goal of the project is to have designed, manufactured, and distributed an initial supply of cover-ups for patients having radiation due to thyroid or thymic-related cancers.

The effort has these objectives:

1. Locate a ready-to-wear cover-up suitable for the target audience. If available, purchase a supply of the cover-ups.
2. If a ready-to-wear product is not available, design and have manufactured a suitable cover-up. The Foundation will hold no patent or copyright on the resulting product, so it may be made available by any other appropriate agency.
3. Identify an initial selection of recipients based on need. These initial wearers will also serve as our test group to identify any changes or variations needed in the design of the cover-up.
4. Once the products are found to be suitable, they will be distributed at radiation and surgery centers across the nation.

Expected Quantifiable Outcomes or Results

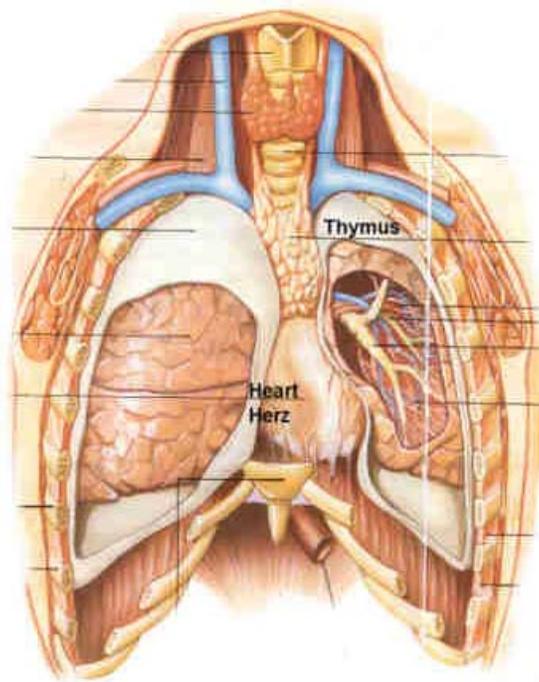
The distribution of the cover-ups is expected to make an immediate improvement on the quality of life of radiation patients.

Method of Evaluation of Proposed Outcomes

The results will be measured through feedback from the patients, care providers, and physicians.

Radiation and Surgery Detailed

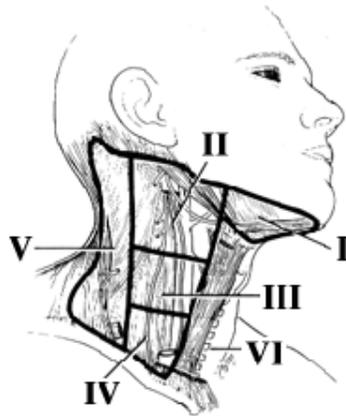
The thymus lies in the upper part of the mediastinum behind the sternum and extends upwards into the root of the neck. It is a pyramid-shaped lymphoid organ between the breastbone and the heart.



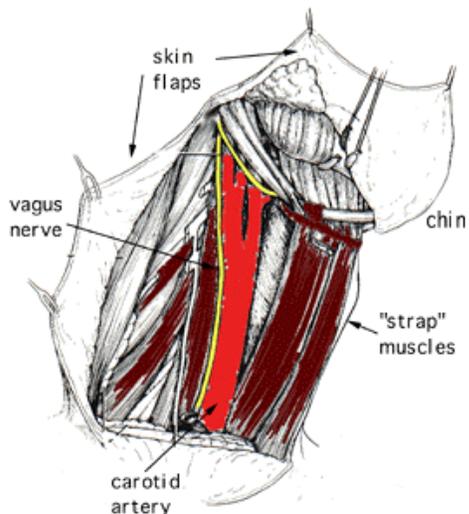
Surgery and radiation for malignant thymomas occurs in the thorax, the upper chest. The exact area depends on the size and involvement of the tumor. Some thymomas have spread too widely to be completely removed. These tumors are usually treated by radiation therapy. Many doctors feel it is important to remove as much of the tumor as is possible before starting radiation. This is called debulking. When the tumor is not operable, radiation therapy, and sometimes chemotherapy, may be used in an attempt to shrink the tumor enough so that it can then be completely resected. After the surgery, radiation therapy will be given.

Other thymic-related cancers, while more rare, occur in the neck. Surgery and radiation occurs either unilaterally or bilaterally, sometimes extending down into the upper mediastinum.

The following image shows the various regions of the neck where the lymph nodes are located. The neck is typically divided into zones, and research has shown that tumors tend to follow certain trends in the manner in which they spread. For example, tumors of the mouth tend to spread first to the upper neck zone (e.g. zones I, II, and III). Tumors lower in the neck, for example laryngeal cancer, tend to spread to lower zones (zones III or IV).



To remove a tumor in the neck area, a neck dissection is performed. Neck dissections are classified by the zones from which the lymph nodes are removed, and whether or not three structures (internal jugular vein, accessory nerve, and sternocleidomastoid muscle) are preserved. If all the nodes are removed (zones I through V) and the three structures are removed it is called a radical neck dissection. A radical neck dissection would be done if the tumor spread to the neck is quite extensive. If the nodes from zones I through V are removed and one of these three structures is preserved, it is called a modified radical neck dissection. And if the operation does not involve all five zones, it is called a selective neck dissection.



The image to the left shows the appearance of the neck after a radical neck dissection. The sternocleidomastoid muscle, the internal jugular vein, and the spinal accessory nerve have been removed. The surgeon has saved the vagus nerve (which supplies the muscles in the throat and the larynx) and the hypoglossal nerve (which supplies the muscles that move the tongue). Also preserved is the carotid artery, which is extremely important for providing oxygen to the brain. The strap muscles are strap-shaped muscles that help raise and lower structures in the neck. Note that skin "flaps" have been elevated,

which allows very good exposure to all the structures in the neck. Exposure is very important in surgery. The important structures to be saved must first be identified, and exposure is key to finding and protecting these nerves and blood vessels.

The classic radical neck dissection removes all of the ipsilateral lymph nodes, the submandibular salivary gland, sternocleidomastoid, internal jugular vein, and spinal accessory nerve. This is associated with multiple functional and cosmetic deformities.

Sacrificing the spinal accessory nerve (cranial nerve XI) results in impaired shoulder movement and the potential development of a painful fixed shoulder from denervating the trapezius muscle.

Removal of the sternocleidomastoid muscle results in a cosmetic deformity, including flattening of the neck on the side of surgery. Removing this muscle results in no real functional deficit in most people.

Removal of the ipsilateral internal jugular vein is tolerated in most people, particularly with modern anesthetic techniques. In most patients, limiting intravenous hydration, both intraoperatively and postoperatively, is important to prevent a syndrome of inappropriate antidiuretic hormone secretion, which has been demonstrated to occur in patients undergoing surgery for head and neck malignancies. Collateral veins, contralaterally and retropharyngeally, prevent significant postoperative edema.

Removal of both internal jugular veins results in significant venous edema and chronic lymphedema of the face and can be fatal in 10% of patients when performed simultaneously. When bilateral jugular vein removal is necessary, stage the procedures at least 1 week apart to permit formation of these collaterals.

For these reasons, various modifications have supplanted most radical neck dissections performed. The modified neck dissection can preserve the internal jugular vein, the spinal accessory nerve, and/or the sternocleidomastoid muscle, provided that lymph nodes containing tumor are not violated.