COUNTY OF SUFFOLK

Steve Levy
SUFFOLK COUNTY EXECUTIVE

DEPARTMENT OF HEALTH SERVICES

BRIAN L. HARPER, M.D., M.P.H.
Commissioner

DAVID G. GRAHAM, M.D., M.P.H.
Chief Deputy Commissioner

ELIZABETH M. HARRINGTON, ESQ.
Deputy Commissioner

July 13, 2005

Dear Rhabdomyosarcoma Task Force Member:

Enclosed is a draft Final Report of Rhabdomyosarcoma Task Force for your comment. I need your comments by August 1 for a completed report that is to be sent to the Suffolk County Legislature. Your work on the Committee is greatly appreciated.

Sincerely yours,

Brian L. Harper, MD, MPH
Commissioner
Task Force Chair

Enclosure

cc Hon. Ginny Fields
Hon. Brian X. Foley
Hon. Paul J. Tonna
Aura Weinstein, M.P.H.
Amy Juchatz, M.P.H.
Edward Nadel, Ph.D., M.P.H.

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Draft Final Report of Rhabdomyosarcoma Task Force

Rhabdomyosarcoma is a rare form of soft tissue cancer that primarily affects children. Less than three cases a year on average occur to children in Suffolk County. In the 1990's the number of Suffolk childhood Rhabdomyosarcoma cases ranged from zero to five per year. During the late 1990's a short term elevation in the childhood Rhabdomyosarcoma rate, relative to the Upstate New York rate, was observed in Suffolk. This observed elevation, together with the concern from a parent group, SEARCH, that the state Cancer Registry database may have been incomplete, led to Suffolk Legislature Resolution 1967-2000 creating a Rhabdomyosarcoma Task Force.

The Task Force directed its attention to two tasks: 1) addressing whether a potential cluster of cases existed in the Smithtown area; and 2) conducting a resident survey to see whether additional cases could be identified that were missed in the state database.

Three Sector Map

Randy Snell, a member of the Task Force and father of a Rhabdomyosarcoma child, had, by word of mouth, heard of several Rhabdomyosarcoma cases in the Smithtown area. Supported by several other Task Force members, he questioned whether there was a cluster of child Rhabdomyosarcoma cases in the Smithtown area. The Task Force agreed to divide the county into three sectors, one in the Smithtown area, one bordering Nassau west of Smithtown and one covering the remaining Eastern townships. Three regions were used because of the rarity of the disease. The areas were defined in terms of zipcodes. After the Task Force agreed to the zipcode composition of the areas, the zipcode lists were forwarded to the NYSDOH Cancer Surveillance Program to analyze with the Rhabdomyosarcoma data for the period 1979-1998. Separately NYSDOH looked at the incidence of all childhood cancers in the same three sectors during the time period. **Appendix 1** shows the tables that resulted. Besides conducting the three sector analysis, NYSDOH also applied the *Satscan* cluster detection algorithm to the data. Neither the three sector map nor the *Satscan* technique detected any statistically significant clustering.

Appendix 2 is an e-mail from the Director of the Cancer Surveillance Program with their conclusion.

Childhood Rhabdomyosarcoma Resident Survey

Following the NYSDOH report on the sector map, the Task Force discussed the possibility that the NYSDOH Cancer Registry might have been missing some Rhabdomyosarcoma cases. Since Rhabdomyosarcoma is such a rare disease, an addition of a small number of cases in some geographic areas may have affected the statistical results. Therefore the Task Force decided to publish a survey form and request that Suffolk residents, aware of any Rhabdomyosarcoma cases, fill out and return the form. NYSDOH agreed to investigate each returned Rhabdomyosarcoma form to see if the case was already in the Cancer Registry, and if not to examine the hospital records to see if it should be classified as Rhabdomyosarcoma. The survey form was adapted from a survey used by NYSDOH to investigate cancer in Elmira NY. The form was published in *Suffolk Life*. In addition, the form was posted on the SCDHS web site in both English and Spanish. The web form, on the SCDHS site, could either be printed out and mailed or sent directly to SCDHS as an e-mail. A press conference with Task Force members, including the Health Commissioner and Legislators Fields

and Foley, was held to publicize the form and encourage public participation in the survey. While the Task Force structured the form to allow all childhood cancer cases to be reported, NYSDOH committed only to investigate the Rhabdomyosarcoma forms.

Although the form only appeared in a couple of issues of *Suffolk Life*, the posting on the SCDHS web site was maintained for two years. All Rhabdomyosarcoma forms, from either the newspaper or the SCDHS web site, were forwarded to NYSDOH for investigation. **Appendix 3** is the NYSDOH report of the survey results. Of the twenty Rhabdomyosarcoma forms investigated, they found one new case that had not been properly classified as Rhabdomyosarcoma in the Cancer Registry. However this case occurred too long ago to have made the time period covered by the childhood Rhabdomyosarcoma sector analysis discussed above.

In sum, the efforts of the Rhabdomyosarcoma Task Force, together with the assistance of the NYSDOH, was unable to yield any additional evidence that either a clustering of childhood Rhabdomyosarcoma cases occurred around Smithtown or that the cases of childhood Rhabdomyosarcoma reported in the New York State Cancer Registry undercounted the number of cases occurring in Suffolk County during the 1979-1998 time period.

BUREAU OF CHRONIC DISEASE EPIDEMIOLOGY AND SURVEILLANCE
NEW YORK STATE DEPARTMENT OF HEALTH

Rates and Confidence Intervals for the Incidence of Rhabdomyosarcoma[1]
in Males and Females Combined, Age 0-19
Suffolk County, New York, 1979-1998

Sector[2]	No. of Cases[3]	Avg. Annual Rate[4] per 100,000	CI	Lower Bound	Upper Bound
Smithtown	22	0.68	0.29	0.39	0.97
Nassau Border	17	0.48	0.23	0.25	0.71
Remainder	7	0.53	0.39	0.14	0.92

[1] Incidence of Rhabdomyosarcoma is defined as having morphology 8900-8920, 8963, 8991, or having ICD9 171 and morphology 8000, 8800, or 9260.
[2] For sector definition see page entitled "List of ZIP Codes in Each Sector".
[3] Data were obtained from the New York State Cancer Registry (database as of November 2001).
[4] Populations are based on linear interpolation from 1980, 1990 and 1999 Claritas Population Estimates.

BUREAU OF CHRONIC DISEASE EPIDEMIOLOGY AND SURVEILLANCE
NEW YORK STATE DEPARTMENT OF HEALTH

Rates and Confidence Intervals for All Childhood Cancers[1]
in Males and Females Combined, Age 0-19
Suffolk County, New York, 1979-1998

Sector[2]	No. of Cases[3]	Avg. Annual Rate[4] per 100,000	CI	Lower Bound	Upper Bound
Smithtown	525	16.3	1.4	14.9	17.7
Nassau Border	590	16.8	1.4	15.4	18.2
Remainder	209	15.8	2.1	13.7	17.9

[1] All Childhood Cancers defined as having an ICD9 of 140-208, 42.2 or 233.7.
[2] For sector definition see page entitled "List of ZIP Codes in Each Sector".
[3] Data were obtained from the New York State Cancer Registry (database as of November 2001).
[4] Populations are based on linear interpolation from 1980, 1990 and 1999 Claritas Population Estimates.

List of ZIP Codes in Each Sector

Smithtown Sector	Nassau Border Sector	Remainder Sector	
11705	11701	06390*	11952
11715	11702	11713	11953
11716	11703	11719	11954
11720	11704	11778	11955
11722	11706	11786	11956*
11727	11717	11789	11957
11730	11718	11792	11958*
11733	11721	11901	11959*
11738	11724	11930*	11960*
11739	11725	11931*	11961
11741	11726	11932	11962*
11742	11729	11933	11963
11752	11731	11934	11964
11755	11735	11935	11965
11763	11740	11937	11967
11764	11743	11939	11968
11766	11746	11940	11969*
11767	11747	11941	11970*
11769	11751	11942	11971
11772	11754	11944	11972*
11776	11757	11946	11973*
11777	11768	11947	11975*
11779	11770*	11948	11976
11780	11795	11949	11977
11782	11798	11950	11978
11784		11951	11980
11787			
11788			
11790			
11794			
11796			

* Additional ZIP Codes, including some point ZIP Codes, that were not included in the original sector definition list but are included in the analysis. For the analysis, all point ZIP Codes were included in the sector of the parent ZIP. The sector for all other ZIP Codes was determined by the ZIP Code's location.

Nadel, Ed

From: Aura L. Weinstein [alw02@health.state.ny.us]
Sent: Tuesday, July 31, 2001 9:14 AM
To: ed.nadel@co.suffolk.ny.us
Cc: Clare.Bradley@CO.SUFFOLK.NY.US; Mark S. Baptiste; Barbara B. Metzger; Francis P. Boscoe; Maria J. Schymura
Subject: rhabdo, update

Ed,

This is in response to your request for information on our examination of childhood rhabdomyosarcoma cases in Suffolk County.

Using the State Cancer Registry, we have taken a more comprehensive look at the geographic distribution of childhood rhabdomyosarcoma cases age 0-19 in Suffolk County since 1979. Based on the suggestion of your task force member Dr. Parker, we have included cases of undifferentiated sarcoma and sarcoma not otherwise specified with an anatomical site of "soft tissue", as well as additional rare histologies included under the grouping rhabdomyosarcoma by the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program; these additional cases made up only a small proportion of the total.

While we are not able to provide you with a map of the cases, we would like to share with you our findings. When we plotted all the cases, the results did not suggest the grouping in the Smithtown area as shown in the map you provided. Since your map only included cases diagnosed from the mid-1980's on, we also looked at the cases by year of diagnosis and still did not see the grouping.

Upon the advice of Dr. Martin Kulldorff, with whom we have been working as part of the Cancer Surveillance Improvement Initiative, Cancer Registry staff are applying two statistical techniques for the detection of clustering to the rhabdomyosarcoma data. The SatScan method applied to both Suffolk County and the entire state by ZIP Code did not identify any statistically significant clusters in Suffolk County. Staff are now working with Turnbull's Cluster Evaluation Permutation Procedure (CEPP).

If you have any questions, you may contact me.

STATE OF NEW YORK
DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza Albany, New York 12237

Antonia C. Novello, M.D., M.P.H., Dr.P.H.
Commissioner

Dennis P. Whalen
Executive Deputy Commissioner

May 2, 2005

DEPT OF HEALTH SERVICES
OFC OF THE COMMISSIONER
2005 MAY -4 AM 7:41

Brian L. Harper, M.D., M.P.H.
Health Commissioner
Suffolk County Department of Health
225 Rabro Drive East
Hauppauge, New York 11788-4290

Dear Dr. Harper:

I am pleased to inform you that the New State Cancer Surveillance Program has completed its case verification investigation of Suffolk County residents diagnosed with rhabdomyosarcoma.

As you know, in an effort to determine if cases of rhabdomyosarcoma in individuals 0-19 years of age were under-reported to the New York State Cancer Registry, Suffolk County residents were asked to complete a brief medical information form if they or a family member had been diagnosed with rhabdomyosarcoma.

A total of 21 reports of rhabdomyosaroma in 20 individuals (one individual was reported twice), were forwarded to our office for verification. These reports were compared with the New York State Cancer Registry information, first to verify that the case had been reported in the Cancer Registry, and then to confirm the diagnosis. As you are probably aware, the Cancer Registry receives information from all hospitals in New York State as well as from various other sources (e.g. New York State Vital Statistics Death Record files) to provide a complete accounting of the burden of cancer for all of New York State.

Of the 20 individuals reported, 18 were confirmed as having been reported to the Registry. For the two individuals not found in the Cancer Registry, one was located in the New York State Vital Statistics Death record files with a nonspecific cause of death code, and therefore was not reported to the Registry as a cancer. We obtained medical records for this individual and the diagnosis of rhabdomyosarcoma was confirmed. (Information on this individual has since been added to the Cancer Registry.) The other individual not found in the Registry was reportedly diagnosed almost forty years ago in a New York City hospital, prior to the institution of mandatory cancer reporting in New York City. For this individual we were unable to confirm the diagnosis since medical records were no longer available.

Of the 19 people who were confirmed to have been diagnosed with cancer, seven were either diagnosed with a cancer other than rhabdomyosarcoma, were not a resident of Suffolk County at the time they were diagnosed, were over the age of 19 at the time of diagnosis, or some combination of the above. Those not meeting the age criteria ranged in age from the mid-20's to late 70's.

The rhabdomyosarcoma survey was conducted to determine whether there might have been cases of childhood rhabdomyosarcoma in Suffolk County residents that were not reported to the New York State Cancer Registry. We confirmed one individual with rhabdomyosarcoma that had not been reported to the Registry. This individual, however, was not a Suffolk County resident age 0-19 at the time of diagnosis. The survey, therefore, provides no basis for recomputing Suffolk County childhood rhabdomyosarcoma incidence rates.

I hope this information will help to address residents' concerns regarding the number of rhabdomyosarcoma cases in Suffolk County. If you have any questions regarding this information or would like to discuss its release, please feel free to contact me at 518-474-2354.

Sincerely,

Aura L. Weinstein, M.P.H.
Director, Cancer Surveillance Program

cc: Dr. Baptiste
Ms. Metzger
Dr. Schymura
Ms. Juchatz
Dr. Nadel