SMART ALACC
Adult Living After Childhood Cancer

Name: _____

MR#: _____

Healthcare Provider Summary

Dear Healthcare Professional

A survivorship care plan was created for or by your patient using the Smart ALACC care plan tool at www.smartalacc.oncolink.org. This report is a summary of the long-term side effects the survivor may be at risk for and recommendations for their follow-up care. The report is generated from the treatment information entered by the patient or their healthcare provider. The summary provided is supported by cancer survivorship literature and expert opinion, but should not replace communication with the patient's oncology team. Suggested management and follow-up points are broken down according to the toxicity-causing treatment (i.e. medical therapy, surgery, or radiation).

Keep in mind that survivors should continue to have screening for other cancers per the American Cancer Society guidelines and routine health maintenance as recommended by the USPTF.

You received the following treatments for Neuroblastoma

- Removal of Abdominal Tumor
- Cyclophosphamide (Cytoxan®, Neosar®)
- Topotecan (Hycamtin®)
- Abdominal Radiation
- X-ray based radiation- IMRT

Information from your oncology office

Follow Up Care for Neuroblastoma

Each pediatric cancer survivor is unique because of their disease processes and exposures. A survivorship care plan is meant to tailor follow up to survivor needs, maximizing prevention of late effects and avoiding unnecessary tests or procedures.

Risks Related to Surgery

Removal of Abdominal Tumor

- In long term follow up, surgeries in the abdomen can infrequently cause abdominal issues such as pain or blockages.

Risks Related to Medications

Risk of Bladder or Urinary Tract Toxicities

- Risks after high-dose cyclophosphamide include hemorrhagic cystitis and decreased bladder capacity,

as well as development of bladder cancer.
- Evaluate for concerning urinary symptoms with urinalysis, urine culture, and urology referral.
- Encourage patients to avoid alcohol and smoking.

Risk of Developing Bladder Cancer

- Encourage smoking and alcohol cessation
- Patients who also received radiation to the pelvis are at increased risk.
- Assess for urinary symptoms at least annually; obtain urinalysis and urine culture for symptomatic patients; and obtain renal/bladder ultrasound and urology referral for patients with culture-negative microscopic or macroscopic hematuria.

Skin Toxicities

- Encourage good hygiene and skin care.
- Evaluate for any signs of infection or non-healing skin wounds.

Learning Differences

- Neurocognitive changes as a result of cancer therapy may include: short term memory, multi-tasking, new learning, reading comprehension, working with numbers and a decrease in concentration ability.
- Cancer survivors should be screened annually with attention to educational/vocational progress.
- Referral to a survivorship program or for neurocognitive testing and cognitive rehab may be of value for survivors with cognitive symptoms.
- Evaluate for treatable causes such as hypothyroidism, depression or anxiety.

Fertility and Sexuality Concerns for Male Survivors

- Due to cancer treatments, survivors may have sexual health (erectile dysfunction, decreased libido) and fertility issues for months to years after treatment.
- Refer to urologist and/or reproductive endocrinologist for symptoms of testosterone insufficiency.
- Refer to urologist and/or reproductive endocrinologist for infertility evaluation and consultation regarding assisted reproductive technologies.
- Bone density evaluation is recommended for androgen deficient patients.

Risk of Developing a Secondary Cancer

- Certain chemotherapy agents or radiation can lead to the development of leukemia, MDS, or lymphoma. This typically occurs 4-10 years after therapy, but could occur as soon as 1-3 years after therapy (early onset is most common with etoposide or teniposide).
- Evidence shows little benefit of sending screening CBCs in the absence of clinical signs/symptoms. Obtain a CBC with differential for concerning signs and symptoms.

Side Effects of Radiation

Long term effects of radiation therapy vary greatly depending on the areas included in the field of radiation and the radiation techniques that were used, as these continue to develop and improve. One issue that is consistent across all tissues is the possibility of developing a second cancer in or near the radiation field. Secondary cancers develop as a result of the exposure of healthy tissue to radiation. Newer radiation

techniques are designed to limit this exposure, but it is not always possible to prevent all exposure and still achieve the desired outcomes.

Abdominal Radiation

- Radiation including the abdomen can affect several organs like the spleen, liver, kidneys and reproductive organs. If the patient was treated as a young child, we sometimes consider abdominal radiation as affecting structures in the chest like heart, lungs or breasts – since children are smaller. This can be discussed with your cancer-follow up team.

Bladder Health

- Radiation that includes the bladder can lead to fibrosis, hemorrhagic cystitis, neurogenic bladder, bladder cancer and make the survivor more susceptible to UTIs.
- Counsel to avoid alcohol and tobacco use.

Maintaining Healthy Skin

- Skin is more sun-sensitive after radiation. Counsel to use sunscreen diligently.
- Evaluation by a wound care specialist for any non-healing ulcers.
- Skin can develop chronic swelling, wounds, changes in texture and color.

Your Spleen After Radiation

- Radiation to the spleen results in a non-functioning spleen (functional asplenia). The spleen can be exposed to radiation during any type of abdominal radiotherapy.
- Patients should receive an annual flu vaccine as well as pneumococcal, Haemophilus influenza type b (Hib), meningococcal and hepatitis vaccines (per CDC recommendations).
- Counsel to seek medical attention at the first sign of fever, with blood cultures to be drawn for a fever of 38.3C or higher in patients who have received 40 Gy or more to the spleen and are thus functionally asplenic.
- Consider providing the patient with "stand-by" antibiotics to be taken at the first sign of a fever. Replace supply periodically to avoid expiration. Be sure they understand the need to still seek medical attention immediately despite the oral antibiotic.
- Patients require immediate attention for an animal bite due to the risk of C. canimorsus.
- Discuss risks of parasitic infestation, particularly malaria, with some international travel. The patient should be seen for any tick bites due to Lyme risk. Exposure to ticks in Cape Cod or Nantucket Island in Massachusetts can lead to infection with Babesia.
- Patients should wear a medic-alert bracelet for notification of "functional asplenia" and can get one from the MedicAlert Foundation.

Liver Health

- Liver function testing before and after cancer treatment including ALT, AST, bilirubin.
- Annual H&P to evaluate for liver disease.
- Counsel to avoid alcohol.
- Refer to a gastroenterologist for any abnormal liver function tests or signs of liver disease.
- Fasting lipid profile every 2 years with referral to a dietitian if results abnormal.

Bowel Health

- Survivors are at risk for scarring and strictures, ulceration and bleeding, chronic diarrhea and poor absorption and fistula formation.
- Immediate medical evaluation for severe abdominal pain, bleeding from the rectum, dark stools or abnormal passage or urine or stools.
- Use anti-diarrheal medicines for chronic diarrhea.
- Consult a dietitian for weight loss or nutritional deficits.
- Screening colonoscopy or DNA stool testing at age 50 for all patients.
    - For those who received abdominal radiation: screening colonoscopy beginning 10 years after radiation therapy (or at age 35, whichever is later), with repeat colonoscopy every 5 years. For patients unable to undergo colonoscopy, and multitarget stool DNA test every 3 years is a reasonable alternative.

Kidney Health

- Annual H&P including hypertension and diabetes screening.
- Annual basic metabolic panel and urinalysis.
- Strict control of blood pressure and blood sugar.
- Evaluation by nephrologist if kidney disease develops.

A Note on Fatigue

- Evaluate any new or worsening fatigue.
- Encourage regular exercise to help combat fatigue.
